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Missing from the debate? A qualitative study exploring the role of communities within interventions to address female genital mutilation in Europe

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2017-021430
Article Type:	Research
Date Submitted by the Author:	28-Dec-2017
Complete List of Authors:	Connelly, Elaine; Scottish Refugee Council Murray, Nina; European Network on Statelessness Baillot, Helen; Scottish Refugee Council Howard, Natasha; London School of Hygiene & Trop Med, Global Health and Development
Keywords:	Violence against women, Female genital mutilation, Europe

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3 **Missing from the debate? A qualitative study exploring the role of communities within**
4 **interventions to address female genital mutilation in Europe**
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28 **Key words**

29 FGM, female genital cutting, community development, Europe
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Abstract

Introduction

Public attention on female genital mutilation in diaspora communities is increasing in Europe, as health and social welfare implications become better understood. This study explored the role of potentially-affected communities within interventions to address female genital mutilation in Europe.

Methods

A qualitative study design incorporated 18 individual key informant interviews and five semi-structured group interviews with policy-makers, service providers, and community representatives. Data were analysed thematically, guided by the Scottish Government '4Ps' framework for addressing violence against women and girls (i.e. prevention, protection, participation, provision of services).

Results

Participants emphasised both the importance of community participation and the lack of consistent engagement by policy-makers and practitioners. All indicated that communities had a key role, though many interventions focussed on awareness-raising rather than community empowerment, behaviour change, or influence on the design, delivery, and/or evaluation of interventions.

Conclusions

Despite clear consensus around the need to engage, support, and empower potentially-affected communities and several examples of meaningful community participation in addressing female genital mutilation, the role of communities remains inconsistent and further engagement efforts are necessary.

Strengths and limitations

- This study was exploratory and participant numbers were limited, including members of potentially-affected communities, due to time and resource constraints.
- Study focus was on European interventions, thus excluding many innovative and successful African interventions.
- Nevertheless, this study is a rare effort to examine the under-researched role of diaspora communities in initiatives to address female genital mutilation in Europe, drawing from in-depth and semi-structured key informant interviews.

Introduction

Female genital mutilation (FGM), a practice (defined in Table 1) that expresses '*deeply entrenched gender inequalities, grounded in a mix of cultural, religious and social facts inherent within patriarchal families and communities,*' is recognised internationally as a violation of the fundamental rights of women and girls and a serious form of gender-based violence (EIGE, 2013). Health implications of FGM are wide-ranging and well-established. Immediate health consequences include shock, haemorrhage, infection, and psychological trauma, while long-term risks include chronic pain, infections, cheloids, primary infertility, urogenital complications, birth complications, and danger to newborns (Kaplan et al, 2011). Though sometimes referred to as 'cutting' or 'female circumcision', this article uses 'FGM' to acknowledge the harm to women and communities.

Data indicate the existence of large communities potentially-affected by FGM in many European countries (Leye et al, 2014; EIGE, 2013). For example, 23,979 people born in one of 29 'FGM-practising countries' (Unicef, 2013), were living in Scotland in 2011 (Baillot et al, 2014). However, attempts to estimate numbers of women and girls who have undergone or are at risk of FGM in diaspora communities in Europe have proven difficult due to data limitations and lack of agreement on prevalence estimation methods (Leye et al, 2014). Additionally, the extent to which migration experiences may change attitudes and practices remains under-researched (Gele et al, 2012). This article uses the term 'potentially-affected communities' to avoid presumptions attached to 'FGM practising communities' that may be inaccurate in a migratory context (Hemmings, 2011).

The concept of community is not straightforward, with a range of contradictory and related meanings used on all sides of the political spectrum (Shaw, 2013). Often defined by geography, interest, or identity, communities are not homogenous or static but rather diverse, dynamic, and multifaceted entities (CDNOS, 2015). This article primarily describes communities of identity, where the common bond is often nationality, ethnicity, and the experience of exile, although some may also be issue-based or geographical.

FGM is described as a '*tradition in transition*' (Berg & Denison, 2013), with some experts asserting that empowering affected communities will lead to its elimination (Gele et al, 2012; Isman et al, 2013; Costello et al, 2013). Public, media, and political attention on FGM in diaspora communities within Europe has increased, but often focuses on criminal justice and child protection (Dustin, 2010). While many European countries have enacted legislation and policy initiatives, the role of communities in interventions addressing FGM remains limited (Dustin, 2010; EIGE, 2013). Little research has been conducted on the role of communities in

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3 FGM interventions and very few have been rigorously evaluated (Brown et al, 2013). Thus,
4 community voices are generally missing from FGM policy debates and partnerships, despite
5 growing consensus that communities are key in addressing FGM (Norman et al, 2009).
6 Working with potentially-affected communities may provide a key opportunity, as the process
7 of migration and exile allows communities to reflect, question, and debate traditional beliefs
8 (Johansen, 2006).
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13 This study aimed to explore the role of communities within interventions to address FGM in
14 Europe, describing perspectives of practitioners, activists, and community representatives on
15 current practices and promising interventions. It is relevant to policy-makers, researchers,
16 community development practitioners, and professionals working with potentially-affected
17 communities.
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22 **Methods**

23 *Study design*

24 A qualitative study design was selected, drawing on data from a scoping literature review
25 (Baillot et al, unpublished) and interviews (i.e. individual and group) with Europe-based
26 academics, legal professionals, statutory and voluntary service providers, community
27 activists, and representatives from potentially-affected communities. The research question
28 was "*What is the role of potentially-affected diaspora communities in interventions that*
29 *respond to and challenge FGM in Europe?*" Table 1 provides definitions used.
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35 *Data collection*

36 *In-depth key-informant interviews* were conducted by EC and HB. Participants were recruited
37 purposively to include academics, policy-makers, police officers, NGO staff, and community
38 activists in EEA member countries with recognised FGM responses. Of 27 invitees, 18
39 participated. Interviews lasted approximately 60 minutes, were audio recorded or scribed
40 depending on permission, and conducted in locations of participants' choosing.
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45 *Semi-structured group interviews* were facilitated by EC and NM. Participants were recruited
46 purposively to include senior and mid-level policy-makers, statutory and voluntary service
47 providers, and community representatives selected for their FGM expertise and activism. Of
48 59 invitees, 36 participated. Discussions lasted approximately 1.5 hours, included 4-9
49 participants, were either audio-recorded or scribed, and facilitated in a central Glasgow
50 venue.
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55 *Analysis and reporting*

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3 Data were analysed thematically. The Scottish Government's strategic approach to
4 preventing and eradicating violence against women and girls '4Ps' framework (i.e.
5 participation, prevention, protection, provision of services) was used for initial deductive
6 coding. Additional themes emerged using inductive coding. EC and NM coded data using
7 *Dedoose* software, with checks by HB. Discrepancies were resolved through discussion and
8 agreement among all authors. Reporting adhered to COREQ criteria for qualitative research
9 (Tong *et al*, 2007).
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13 14 *Ethics*

15 The Research Ethics Committee of the London School of Hygiene & Tropical Medicine
16 granted ethics approval (reference 7977).
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20 **Findings**

21 Table 2 shows 18 individual interviews were conducted with participants working EU-wide
22 and/or in seven countries with active interventions addressing FGM (i.e. Belgium, England,
23 France, Ireland, Netherlands, Scotland, Spain). Five group interviews were conducted with a
24 total of 36 policy-makers, service providers, and community representatives. Community
25 participants, from Sudan, Somalia, Gambia, and Uganda, were activists or representatives of
26 voluntary or community-led organisations working to address FGM.
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32 The role of communities is reported under the four framework themes and one emergent
33 theme of barriers to involvement. Sub-sections include analysis of the extent to which
34 potentially-affected communities were involved in addressing FGM in Europe.
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38 *Participation*

39 Four participation sub-themes emerged: (i) communities' vital role, (ii) engagement and
40 representativeness, (iii) involvement in campaigns, and (iv) the value of a clear and inclusive
41 national strategy.
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46 *Vital role:* Literature and interview sources highlighted that empowering affected communities
47 was the only way to end FGM (Costello *et al*, 2013; Gele *et al*, 2012; Isman *et al*, 2013;
48 Khaja *et al*, 2009). All participants emphasised the key role of potentially-affected
49 communities, indicating it was vital to ensure interventions were informed by the
50 experiences, needs and views of those affected by FGM.
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53 *'Anything around FGM needs to be championed and developed with people affected at*
54 *the centre and leading the work.'* (CG1)
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3 Supporting and enabling community organisations to participate in policy-making was
4 identified as essential.

5 *'Finding ways and mechanisms to give [community organisations] that capacity, the*
6 *framework and leverage for them to be heard [is] very important because I don't*
7 *believe we can effectively abandon FGM in Europe [...] if those communities are not*
8 *the ones...acting for the abandonment of FGM. It's a very important role and only they*
9 *can actually do it.'* (KIF10)

13
14 *Engagement and representativeness:* Despite consensus on its value, most participants said
15 insufficient efforts were made by policy-makers and practitioners to engage with communities
16 (KIF06; KIF01; KIF07; KIF17; KIF18). This was particularly evident in the UK, with existing
17 approaches described as *'piecemeal'* (KIF15) and *'tokenistic'* (KIF17; KIF18). Community
18 participants cited examples of being excluded or included at the last minute to *'tick a box'*
19 (KIF17) or when statutory professionals had a crisis (KIF18). In contrast, engagement in the
20 Netherlands was described as *'active'* (KIF05; KIF18).

21
22 *'I don't think there's any such thing as a hard-to-reach group. I think there's*
23 *something called 'failed-to-reach groups by the statutory agencies' because there'll*
24 *always be individuals or an organisation who'll get you access to affected*
25 *communities.'* (KIM12)

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32 Participants noted a tendency of UK decision-makers to engage with the same handful of
33 individuals as *'leaders'* or *'spokespeople'* (KIF18). One highlighted the difference between
34 enabling individual community members to participate and working with community
35 organisations.

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37 *"[Community organisations] are bringing more than just their personal opinion, they*
38 *tend... to be engaging more widely with the community and so can be a channel to*
39 *have these voices heard."* (KIF18)

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44 Representativeness appeared to be a particular challenge for countries newer to FGM issues
45 (e.g. Portugal) as community organisations might not yet exist around this issue or have
46 confidence and advocacy experience (KIF18). Thus, whether effective or *'active'* participation
47 was achieved appeared to vary between - and sometimes within - countries, potentially
48 depending on whether decision-makers valued community organisations.

49
50 *"It depends... whether the local authority [...] values community interventions and*
51 *whether they see the community as a problem and... statutory professionals as the*
52 *answer...or whether [the local authority] views the community as part and parcel of*
53 *[...] the solution."* (KIF18)

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4 UK participants noted that most FGM work occurred in silos, further challenging effective
5 participation. Interventions focused solely on FGM failed to account for '*gendered social*
6 *norms... and nature of women's lives*' (KIF15). Participants indicated that separating FGM
7 from issues like domestic violence was a major problem.
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10 *"They are seen as completely separate topics or discrete topics as opposed to how*
11 *do these principles cut across the way we navigate our communities and navigate our*
12 *spaces."* (KIF18)
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16 *Campaigns:* Several participants said that communities played an important role in
17 campaigning and awareness-raising. The Europe-wide End FGM Campaign led by Amnesty
18 International Ireland and the lobbying work of GAMS, a large French NGO founded in 1982
19 by women of African and Western origin, were highlighted (KIF02). Others spoke of the
20 important work of high profile survivor-campaigners, such as Layla Hussein in the UK
21 (KIF07). One participant talked about her own role as a community campaigner in '*raising*
22 *awareness through fashion...music and culture nights*' and '*campaigning, lobbying and*
23 *working with the government*' (KIF07).
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29 *Strategy:* Several participants noted that addressing FGM required strong strategic
30 frameworks. Most suggested this should be a resourced, standalone, multi-agency, national
31 action plan, developed in partnership with key stakeholders, including affected communities:
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34 *"Authorities should... design a plan of action on FGM and...attach a budget to it and [it]*
35 *should not only be developed by officials in their offices but in collaboration with the*
36 *communities themselves and with all stakeholders."* (KIF06)
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40 At least eight European countries had developed national FGM action plans by 2013 (EIGE,
41 2013) and Scotland did so in 2016 (Scottish Government, 2016). There were very few
42 examples across Europe of communities having a role in strategy development or being
43 supported to influence policy and practice. The Finnish National Action Plan provided an
44 example of community engagement, as it was developed by a working group of government
45 ministries and African women's organisations (EIGE, 2013). Scotland's national action plan
46 incorporated clear actions on community participation, but participants noted limited
47 engagement with communities in its development (KIF17) and a general absence of
48 community voices in the policy arena in Scotland (CG1; CG2; KIF17). Participants in several
49 European countries noted disconnects between policy and reality.
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3 *“One thing we’re missing which is the reality for many European countries, is the*
4 *grassroots... There’s a lot of awareness and there’s a lot of policy but somehow we don’t*
5 *understand what’s happening at the grass roots.” (KIF07)*
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8 *Prevention*

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10 Prevention sub-themes that emerged were: (i) women’s leadership; (ii) roles of men, youth,
11 and religious leaders; and (iii) effective prevention interventions.
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14 *Women’s leadership:* Participants identified women from potentially-affected communities,
15 including survivors, as playing key roles in addressing FGM. Provided they had the trust and
16 respect of their communities, these ‘*knowledgeable cultural guides*’ (Khaja et al, 2009) were
17 considered central to changing community behaviours. A participant explained that while ‘*it*
18 *doesn’t need to be a survivor...you do need someone from that community*’ (KIF07). Norman
19 and colleagues noted the effectiveness of messages from within communities:
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22 *‘Women’s arguments against FGM, spoken fluently and in their own words and*
23 *crucially, coming from within the community, provide an important resource for those*
24 *working to end FGM.’ (Norman et al, 2009)*
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29 A UK participant highlighted the significance of a women-led ‘*African diaspora organisation*’
30 addressing FGM:
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32 *“People recognize that we seem to have some kind of understanding of the issues...
33 We...brought a woman from Somalia to deliver a session on social services and
34 safeguarding children. It was a different dynamic... because this is somebody from the
35 community talking about these issues.” (KIF15)*
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40 *Roles of men, youth, and religious leaders:* While women from affected communities have
41 been vital in prevention interventions, participants identified the important male role that was
42 often missing.
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44 *‘Something that’s really missing is when we talk about the community, we always*
45 *target women, but what about the men, are they not part of the decision-making?*
46 *FGM is not only the woman’s decision.’ (KIF07)*
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50 Male perspectives provided deeper reflection about cultural complexities surrounding FGM
51 and the most common arguments for its continuation (Ruiz et al, 2014). One participant
52 noted that men were increasingly involved and no longer viewed FGM as strictly ‘*women’s*
53 *business*’ (KIF02). Another participant noted that men in migratory contexts were far more
54 likely to be involved than in countries of origin (KIF09). In the Netherlands, involving men was
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3 common:

4 *'I never heard it was difficult to involve men and the men I've spoken with are very*
5 *passionate.'* (KIF05).
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8 Participants identified young people as critical *'advocates of change'* (KIF15) and *'parents of*
9 *the next generation'* (KIF04), able to speak freely about FGM and more likely to become
10 involved in community activism. One participant noted that young people were most at risk of
11 FGM and so educating and working with young people was vital if girls were expected *'to*
12 *come forward and express their fear of having FGM'* (KIF17). Examples of effective work with
13 British young people included Daughters of Eve, Integrate Bristol, and FORWARD. In Ireland
14 and the UK, young people were involved in projects including *'using films and resources to*
15 *support [...] statutory professionals in schools'* (KIF07), and developing poetry, radio
16 documentaries, films, and music videos to *'encourage that conversation to happen in as*
17 *many different settings as you can'* (KIF04).
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24 Religious leaders influenced many communities and therefore could play a *'pivotal and*
25 *respected role'* (Khalifa & Brown, 2016). As one participant stated, *'in our community when*
26 *we are worried about anything we contact our religious leaders'*, suggesting involvement of
27 religious leaders could be key (KIF17). Most religious leaders were men, potentially easing
28 work with other men (KIF17). However, another source noted the need *'to critically examine*
29 *the added benefit'* as preventative work had challenged the religious justifications of FGM
30 without necessarily involving religious leaders (Khalifa & Brown, 2016).
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37 *Effective interventions:* The World Health Organisation (WHO) recommended a shift from
38 awareness-raising to behaviour change approaches in 2009 (EIGE, 2013). However, despite
39 some exceptions, prevention interventions focused on awareness-raising rather than
40 empowerment and targeted behaviour change (EIGE, 2013; Brown et al, 2013). Awareness-
41 raising approaches often had broad target audiences and aims rather than focusing on
42 communities most at risk. Thus, *'key targets ...may not be fully reached or engaged'* (EIGE,
43 2013). Equally, approaches that focused on individual change, without acknowledging
44 community belief systems, have resulted in slow progress addressing FGM across Europe
45 (Brown et al, 2013). When community organisations and statutory professionals worked
46 together on prevention work, using joint messages on ending FGM, FGM rejection reportedly
47 increased (Brown et al, 2016, Khalifa & Brown, 2016; Esmee Fairbairn, 2013).
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54 Participants identified EU-funded REPLACE and REPLACE2 programmes as effective
55 prevention interventions, focused on Belgium, England, Italy, the Netherlands, Portugal, and
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3 Spain. REPLACE developed a toolkit for conducting participatory action research (PAR) with
4 communities and a behaviour change cycle framework for enabling community members to
5 take action to end FGM (Brown et al, 2013). Enabling community members themselves to
6 gather data from within their communities ensured that '*research is conducted 'with' rather*
7 *than 'on' the community*' (Brown et al, 2013).
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10 "[REPLACE is] *innovative because it focuses on behaviour change; it works directly*
11 *with the communities, which is quite exceptional in Europe [...It is] framed in a theory of*
12 *behaviour change, which really has a thorough methodology... and also an evaluation.*"
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14 (KIF06)
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17 Participants identified PAR approaches generally as good practice, able to provide in-depth
18 understanding of the interventions needed with particular communities. Participants identified
19 a PAR initiative called Participatory Ethnographic Evaluation and Research, developed by
20 Options and Swansea University, as "*an eye opener for a lot of the community members*"
21 (KIF15) who recognised that FGM must be addressed in their community and went on to play
22 key roles in other FGM interventions.
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28 Participants described *Ketenaapak* ('Dutch Chain Approach') in the Netherlands as
29 particularly effective. This model was described as a '*meaningful initiative to involve*
30 *communities in FGM prevention work and a landmark in the prevention of FGM in the*
31 *Netherlands*' (EIGE, 2013). In this multi-disciplinary approach, over 100 key community
32 figures contributed to child protection and prevention through organising home visits and
33 meetings within their communities to raise FGM awareness (KIF05). Several participants
34 identified the *Federation of Somali Associations in the Netherlands (FSAN)* as a grassroots
35 organisation playing an important role in identifying key figures within communities,
36 coordinating activities, and providing training (KIF02; KIF03),
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43 The Tackling FGM Initiative (TFGMI), established in the UK in 2010, was a six-year
44 collaboration between five funding bodies to strengthen community-based preventative work
45 (Brown & Porter, 2016). It provided many examples of good practice focused on community-
46 led prevention and participation in activities across the UK, highlighting the crucial role of
47 community 'champions' supported by community organisations (Khalifa & Brown, 2016). For
48 example, a Manor Gardens training programme enabled London women and men to become
49 paid Community Facilitators and work with healthcare professionals to organise FGM
50 sessions (KIF18). Another example, Africa Advocacy Foundation, relied on social networks
51 to create '*sister circles*' (safe spaces for women) to enable community conversations around
52 FGM in South East London (Khalifa & Brown, 2016). Safe, women-only spaces were
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3 considered important '*for women to discover for themselves the nature of their reality through*
4 *discussions with other women*' (Dominelli, 1995), as a first step in rejecting FGM (Khalifa &
5 Brown, 2016). As one participant noted, '*one of the mistakes we make is that we assume*
6 *everyone knows that FGM is harmful whereas many women from communities or women*
7 *who have experienced FGM don't see that*' (KIF17).
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10 11 *Protection*

12 Two emerging protection sub-themes were (i) prevention-protection linkages and (ii) effective
13 protection.
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17 *Prevention-protection linkages:* Despite consensus that legislation and criminal justice
18 approaches helped provide an enabling framework for prevention work, participants noted
19 that such approaches could not succeed without a parallel focus on prevention.
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22 *"Given the deep-rooted cultural nature of harmful traditional practices, we can mount*
23 *as many arrests as we possibly can [...], but unless...an affected community changes*
24 *their thinking, then we're never going to truly...prevent or...eradicate these practices."*
25
26 (KIM12)
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29 Prevention and protection were described by one participant as '*two sides of the same coin,*
30 *neither can succeed without the other*' (KIF14). However, there are recognised tensions
31 between these approaches (Berer, 2015, EIGE, 2013). Preventive approaches are generally
32 more collaborative (EIGE, 2013) and community-focused (Berer, 2015). Protection
33 approaches, whilst perhaps necessarily promoting an unequivocal message around child
34 protection, may lead to families being viewed as potential perpetrators (EIGE, 2013). Several
35 participants highlighted that culturally aggressive top-down approaches imposed on
36 communities, without the building of trust between families and professionals, could have
37 unwanted consequences, e.g. girls being taken abroad for FGM (KIF01; Gele et al, 2012) or
38 already marginalised families, pushed further from mainstream society, '*cling[ing] to their*
39 *own cultures and traditions more tightly*' (Berer 2015).
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47 Participants in France and the Netherlands reported some success in achieving attitudinal
48 change and reducing FGM through a combination of prevention and protection interventions.
49 In France, a number of high profile prosecutions and legislative measures had been
50 accompanied by investment in training and support for professionals, as well as education
51 and awareness-raising in schools and universities, though the role of communities was not
52 necessarily clear within this (KIF02). In the Netherlands (i.e. *Katenapaak*), participants
53 reported most success developing a crucial role for communities within combined prevention
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3 and protection responses (KIF05). UK approaches were criticised for failing to effectively link
4 protection and prevention agendas and involve communities: “...efforts to reduce FGM have
5 focused on punitive legislation without at the same time empowering women in communities
6 to engage in debate, change attitudes and create alternative ways of affirming their cultural
7 identity” (Dustin, 2010). However, describing a successful Police-led community conference,
8 a UK participant suggested that this was shifting, with many organisations ‘*motivated by the*
9 *need for change*’ and prepared to support the police in developing ‘*community-driven*’
10 solutions (KIM12).
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16 *Effective protection:* Participants highlighted community involvement in protection
17 interventions in the Netherlands, UK, and Spain. UK participants noted statutory agencies
18 involving community organisations at an earlier stage when girls were identified as at risk of
19 FGM (KIF17, KIF18). For example, FORWARD in London and NEw STep for African
20 Community (NESTAC) in Manchester worked alongside authorities to deliver family
21 education sessions, overcoming language and cultural barriers to strengthen engagement
22 (KIF18). In Bristol, social services increased the capacity of community organisations to take
23 on ‘safeguarding’ roles, working together to ensure common understandings of risk (KIF18).
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29 However, some participants expressed reservations about communities’ role in protection
30 interventions, suggesting that statutory agencies passing on risk management responsibility
31 to community organisations was risky (EG1; KIF18). Another noted that community
32 organisations with experience of case management, e.g. around violence against women or
33 asylum-seekers, could better manage the complexities of taking on a protection role (Khalifa
34 & Brown, 2016). A participant described the value of joint-working, in building community
35 confidence to report concerns.
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40 *“If there is a cutter in the community, the chances are higher that the community*
41 *members would be aware of it than a professional...we need to work with*
42 *communities to train them and empower them...so they can report for themselves.”*
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44 (KIF17)
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47 Other examples included developing tools to support protection of individual women and
48 girls. The Dutch Government produced a passport-sized declaration, signed by a range of
49 community and non-community organisations, stating that FGM is forbidden and punishable
50 by a prison sentence and loss of rights to residency, which families can carry when travelling
51 overseas (KIF05). A Spanish region produced a similar official letter for families travelling
52 abroad (KIF01). Participants highlighted the need for such tools to be developed in
53 partnership with communities, as in the Netherlands. UK participants noted that when a
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3 similar tool was developed by the UK Government, communities did not feel ownership of it,
4 lessening its impact (KIF15).
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7 *Provision*

8 Two emerging services provision sub-themes were (i) provision roles and (ii) facilitating
9 access.
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13 *Provision roles:* Participants identified community organisations across Europe providing
14 services from advocacy to psychological support, e.g. Daughters of Eve, FORWARD, FSAN,
15 and GAMS - the *Groupe pour l'Abolition des Mutilations Sexuelles* (KIF03; KIF06, KIF15;
16 KIF17). Fewer examples existed of community organisations influencing the planning, design
17 or delivery of services, although participants concurred on the need for this (KIF17; KIF15;
18 KIF18).
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22 *"If communities are involved they can tell what kind of services they require, rather*
23 *than...you know coming from top down, where they make assumptions."* (KIF17)
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26 *Facilitating access:* Although community organisations seldom delivered clinical services,
27 they had an important role in facilitating women's engagement *"to understand why that*
28 *service exists and... taking the time to explain it ...which is something that many health*
29 *providers don't have the time to do"* (KIF17). UK participants described community
30 involvement in developing and delivering specialist services (KIF15; KIF18). For example, an
31 FGM clinic in Bristol was developed in response to lobbying from women who were involved
32 in its design and sat on its steering group (KIF18). A London project, developed to support
33 women failing to attend specialist appointments at an FGM clinic, involved community
34 members calling/meeting clients to explain appointments, which improved services uptake
35 (KIF18).
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43 In response to such barriers as a reluctance to disclose FGM to health professionals (KIF05),
44 a fear of being criminalised (KIF17), or a lack of trust (KIF18), compounded by health
45 providers' own discomfort and reluctance to initiate discussions around FGM (Abdulcadir et
46 al, 2014), community organisations and members were regarded as having a key role in
47 facilitating access to services. Participants identified an example of a service employing
48 outreach workers from the community who take on a '*mediating role*' (KIF18). In another
49 example, the Dutch Government funded a community organisation to implement an
50 awareness raising campaign to get information to women about services available to them
51 (KIF05). Another participant described a more informal role.
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3 *"I often get people phoning me asking for advice and support... A lot of women would*
4 *say that they don't want to ask someone outside [...] So we need... a way... to give*
5 *confidence to women to be able to speak to their GP or health visitor about their fear of*
6 *FGM without feeling criminalised."* (KIF17)
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10 Many participants highlighted the gap between communities and statutory agencies and the
11 need for engagement models that facilitated improved trust, confidence, and access (KIF15;
12 KIF15; KIF18; KIF17; KIF08).

16 *Barriers to community participation*

17 The main barriers identified to effective work with communities were: (i) cultural, i.e. within
18 communities; (ii) structural, i.e. external to communities; and (iii) sustainability-related.

21 *Cultural:* Leadership of FGM work is not easy and participants described the importance of
22 supporting community-members taking on such roles, e.g. through training, information, and
23 access to services (KIF05; KIF13; KIF13). Negative consequences for community leaders or
24 activists have been documented (Behrendt, 2011), including verbal abuse, criticism, threats,
25 and family conflict (KIF05; KIF04; KIF17).

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29 *"I've had people from my community who have sent me...hate messages, saying...*
30 *what you're doing is wrong. And I've had family-members who have said that they*
31 *will no longer speak to me... and that I... bring shame on them. It's not... easy for me*
32 *to take on this role. Trust me, there were times when I almost gave up"* (KIF17)
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37 Women may worry about bringing shame on their communities or experience shame or guilt
38 if they speak about FGM to service providers or other 'outsiders' (KIF17; KIF16; Vloebergs,
39 2013), particularly as some communities are explicitly told not to speak about FGM (KIF17).
40 Trust-related barriers were thus common between communities and professionals (KIF07;
41 KIF04), particularly within child protection (KIF18) or health services, where usage of
42 interpreters could compound trust issues (KIF16; KIF17). Taking time to build trust was
43 therefore deemed important

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47 *'It's not a case of turning up with knowledge, but of starting off with the knowledge of*
48 *communities themselves, then building something together'* (KIF02)
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51 Gender norms and power dynamics within potentially-affected communities were identified
52 as potential barriers, with several participants highlighting the importance of working with
53 men and women separately before bringing them together if appropriate (KIF04; KIF07).
54 While gender oppression was a structural barrier experienced by women globally, "its
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3 *manifestation differs according to culture, country and social grouping*' (Dominelli, 2011) thus
4 affecting which avenues were open to women to challenge or engage with FGM.
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7 *Structural:* Lack of understanding among professionals of the value and potential role of
8 communities was highlighted as a key barrier to their involvement in interventions. Key
9 decision-makers and service providers would need to change the ways in which they work to
10 ensure that communities were actively involved and heard. One participant provided an
11 example of statutory professionals in Bristol who developed alternative ways of engaging
12 with communities including attending community events, holding informal consultations, and
13 making meetings and meeting space more equitable and community friendly (KIF18). Lack of
14 compensation for travel and childcare expenses was cited as a barrier by several
15 participants, including a lack of understanding by some professionals of why such expenses
16 would even be required (KIF06; KIF17; KIF18).
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19 *'It still feels like there is a need to explain the added value of communities to the*
20 *powers that be.'* (KIF18)
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26 *Sustainability:* Participants in different contexts raised concerns about the sustainability of
27 FGM interventions, particularly those at community level that required long-term investment.
28 Some indicated that although community-led organisations were often approached for their
29 expertise, they were rarely funded for this advisory role (KIF15) and that significant
30 government funding was needed (KIF06; KIF15). Others highlighted the need for longer-term
31 investment in implementation and action beyond developing protocols, frame-works, and
32 action plans (KIF15; KIF03). Several noted that much of the work of community organisations
33 was not financially valued, with one participant stressing how important it was to recognise
34 the challenging nature of this work, which is *'under-valued and under-resourced'*, and
35 questioning how long community members could continue to volunteer in such challenging
36 roles (KIF15).
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44 **Discussion**

45 *Principle findings*

46 Clear consensus emerged that potentially-affected communities should have a role in all
47 intervention areas and that this was vital to addressing FGM in Europe (EIGE, 2013; Brown
48 et al, 2013; Khalifa & Brown, 2016). Despite this consensus and several examples of good
49 practice, community roles remained inconsistent in FGM interventions and often non-existent
50 in FGM policy development. Most FGM interventions across Europe focused on awareness-
51 raising, and despite some examples of good practice, community participation appeared
52 fairly minimal (Brown et al, 2013; EIGE, 2013). The extent of community participation varied
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3 between and within countries. While community participation was accepted as vital, practices
4 associated with community participation varied enormously. This corresponded with the
5 significant literature highlighting challenges inherent in increasing community participation,
6 e.g. what level of participation (Arnstein, 1969, Cornwall, 2015), '*who participates, in what,*
7 *and for whose benefit*' (Cornwall, 2015), and to what extent government organisations that
8 engage with communities could change to develop truly participatory processes and spaces
9 (Eversole, 2012).
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14 The role of communities appeared most developed within prevention interventions, with good
15 practice examples of both community-led initiatives and partnership. Protection-focused
16 approaches were more challenging in terms of participation, as the clear child-protection
17 focus could stigmatise families (Gele et al, 2012, EIGE, 2013). Community participation
18 within safeguarding varied, with examples of both effective and emerging roles. Individuals
19 and organisations had roles in building trust and bridging gaps between communities and
20 authorities, though responsibility for managing risk should remain firmly with statutory bodies
21 (Khalifa & Brown, 2016). While several community-led organisations delivered a range of
22 services, few examples were found of communities participating in designing, delivering or
23 evaluating statutory services. Good practice examples were identified of community
24 organisations or activists playing a key role in facilitating services access and enabling
25 dialogue within communities to occur (Khalifa & Brown, 2016).
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33 34 *Implications for policy and practice*

35 Engaging potentially-affected communities in coordinated multi-agency responses appears
36 critical to the success of FGM policies and interventions in Europe. Decision-makers and
37 service providers should invest in community engagement by (i) ensuring that community
38 organisations can participate actively in future interventions and (ii) addressing cultural,
39 structural, and sustainability-related barriers to participation.
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44 Supporting and strengthening community organisations can improve engagement. Bottom-up
45 approaches that enable dialogue within communities appear most successful. Community
46 development support could enable potentially-affected communities to identify their own
47 FGM-related concerns and aspirations and work collectively to identify solutions and take
48 action. This requires long-term investment in community development support and
49 community organisations themselves, to support community-led interventions and
50 meaningful engagement between communities and policy-makers.
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3 Research on FGM interventions across Europe is limited, when compared to levels of
4 activism. Research has focused on clinical care, provision of health services, and attitudes
5 towards FGM. Minimal investigation has been conducted on the role of diaspora
6 communities and their contributions to challenging and responding to FGM. Empowerment,
7 engagement, and participation are frequently mentioned, but rarely critically examined, with
8 little discussion about how to move beyond rhetoric towards putting these concepts into
9 practice. Further research with communities, including participatory methods, appears
10 warranted.
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16 *Limitations*

17 This study had three significant limitations. First, this study was exploratory and participant
18 numbers were limited due to time and resource constraints. Second, numbers of participants
19 from potentially-affected communities were limited and further community engagement is
20 needed to expand on issues raised. Finally, focus on European interventions ignored the
21 successfully designed and implemented African interventions (e.g. TOSTAN;
22 www.tostan.org) that offer international benchmarks for changing attitudes and reducing
23 FGM (Baillot et al, 2014).
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29 **Conclusion**

30 Exploring the role of communities within interventions to address FGM in Europe allowed
31 critical examination of how crucial community voices remain marginalised and could be
32 better heard and supported. “*Without an effective commitment to the participation and*
33 *empowerment of potentially-affected communities, policy-makers and practitioners will not*
34 *identify the actual risks experienced by diaspora girls and women in Europe or develop*
35 *effective interventions, and risk further marginalising those community voices that are the*
36 *most effective advocates for change” (Baillot et al, 2014). Results demonstrate that it is*
37 *possible to work alongside potentially-affected communities, benefitting from community*
38 *perspectives and expertise, to develop meaningful partnerships and support community-led*
39 *interventions.*
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47 **Declarations**

48 *Conflict of interest*

49 None declared.
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52

53 *Author contributions*

54 EC contributed to study design, data collection and analysis and drafted the manuscript. NM
55 contributed to study design, data analysis, and manuscript writing. HB contributed to study
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3 design, data collection and analysis, and critically reviewed the manuscript. NH contributed
4 to study design and data interpretation and critically revised the manuscript. All authors
5 approved the version for submission.
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7

8 *Acknowledgements*

9
10 Special thanks to key informants, particularly women from potentially-affected communities,
11 for their invaluable insights.
12
13

14 *Funding*

15
16 This work was supported by the Scottish Government Equality Fund and Rosa FGM Small
17 Grants Programme for funding research.
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20 *Data sharing*

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22 Anonymised dataset and coding are available on request in accordance with LSHTM
23 institutional data management policy.
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Tables

Table 1. Key definitions

Female genital mutilation	All procedures that involve partial or total removal of the female external genitalia, or other injury to the female genital organs for non-medical reasons (WHO, 2016)
Community	A community of identity has a common bond based on ' <i>geography, identity or interest</i> ' (CDNOS, 2015)
Community development	Community development enables people to work collectively to bring about positive social change. This long-term process starts from people's own experience and enables communities to work together to: <ul style="list-style-type: none"> • identify their own needs and actions; • take collective action using their strengths and resources; • develop their confidence, skills and knowledge; • challenge unequal power relationships; • promote social justice, equality and inclusion; to improve the quality of their own lives, the communities in which they live and societies of which they are a part (CDNOS, 2015)
Participation	Policy-making and practice development around violence against women is shaped by the experiences, needs and views of those affected by FGM (Baillot <i>et al</i> , 2014).
Potentially-affected community	A diaspora community from one of 29 countries identified by Unicef, in which FGM practices are concentrated, i.e. Somalia 98%, Guinea 96%, Djibouti 93%, Egypt 91%, Eritrea 89%, Mali 89%, Sierra Leone 88%, Sudan 88%, Gambia 76%, Burkina Faso 76%, Ethiopia 74%, Mauritania 69%, Liberia 66%, Guinea-Bissau 50%, Chad 44%, Cote d'Ivoire 38%, Kenya 27%, Nigeria 27%, Senegal 26%, CAR 24%, Yemen 23%, Tanzania 15%, Benin 13%, Iraq 8%, Ghana 4%, Togo 4%, Niger 2%, Cameroon 1%, Uganda 1% (Unicef, 2013)
Prevention	Interventions intended to create and/or sustain behavioural and attitudinal change within affected communities (Baillot <i>et al</i> , 2014)
Protection	Interventions intended to protect the individual rights of women and girls who are at risk of or have experienced FGM (Baillot <i>et al</i> , 2014)
Service provision	Service responses to survivors of FGM (Baillot <i>et al</i> , 2014)

Table 2. Participant characteristics

ID	Role/Title	Location	Interview type
KIF01	University Professor	Spain (Skype)	KII
KIF02	NGO Worker	France	KII
KIF03	NGO Worker	Netherlands	KII
KIF04	Teacher	England	KII
KIF05	Government Minister	Netherlands	KII
KIF06	University Professor	Belgium	KII
KIF07	Community Activist	Ireland (Skype)	KII
KIF08	Medical Professional	England	KII
KIF09	University Professor	France	KII
KIF10	INGO Worker	EU	KII
KIF11	Solicitor	Scotland	KII
KIM12	Chief Superintendent	England	KII
KIF13	Chief Inspector	England	KII
KIF14	Legal professional	France	KII (unrecorded)
KIF15	NGO Worker	England	KII
KIF16	Medical professional	Scotland	KII
KIF17	Community Activist	Scotland	KII
KIF18	Community Activist	Scotland	KII
EG1	9 policy/practice participants	Scotland	Group interview
EG2	9 policy/practice/community participants	Scotland	Group interview
EG3	10 policy/practice/community participants	Scotland	Group interview
CG1	4 community activists	Scotland	Group interview
CG2	4 community activists	Scotland	Group interview

BMJ Open

Missing from the debate? A qualitative study exploring the role of communities within interventions to address female genital mutilation in Europe

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2017-021430.R1
Article Type:	Research
Date Submitted by the Author:	28-Mar-2018
Complete List of Authors:	Connelly, Elaine; Scottish Refugee Council Murray, Nina; Scottish Refugee Council Baillot, Helen; Scottish Refugee Council Howard, Natasha; London School of Hygiene & Trop Med, Global Health and Development
Primary Subject Heading:	Public health
Secondary Subject Heading:	Health policy
Keywords:	Violence against women, Female genital mutilation, Europe

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3 **Missing from the debate? A qualitative study exploring the role of communities within**
4 **interventions to address female genital mutilation in Europe**
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26 **Key words**
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28 FGM, female genital cutting, community development, Europe
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Abstract

Introduction

Public attention on female genital mutilation in diaspora communities is increasing in Europe, as health and social welfare implications become better understood. This study explored the role of potentially-affected communities within interventions to address female genital mutilation in Europe, examining current practices, promising interventions, and remaining gaps.

Methods

A qualitative study design incorporated 18 individual key informant interviews and five semi-structured group interviews with policy-makers, service providers, and community representatives. Data were analysed thematically, guided by the Scottish Government '4Ps' framework for addressing violence against women and girls, i.e. prevention, protection, provision of services, and participation.

Results

Participants emphasised both the importance of community participation and the lack of consistent engagement by policy-makers and practitioners. All indicated that communities had a key role, though most interventions focussed on awareness-raising rather than community empowerment, behaviour change, or influence on the design, delivery, and/or evaluation of interventions.

Conclusions

Despite clear consensus around the need to engage, support, and empower potentially-affected communities and several examples of meaningful community participation in addressing female genital mutilation (e.g. REPLACE, REPLACE 2, *Ketenaapak*, Tackling FGM Initiative), the role of communities remains inconsistent and further engagement efforts are necessary.

Strengths and limitations

- This study was exploratory and participant numbers were limited, including members of potentially-affected communities, due to time and resource constraints.
- Study focus was on European interventions, thus excluding many innovative and successful African interventions.
- Nevertheless, this study is a rare effort to examine the under-researched role of diaspora communities in initiatives to address female genital mutilation in Europe, drawing from in-depth and semi-structured key informant interviews.

Introduction

Female genital mutilation (FGM), a practice, defined in Table 1, that expresses '*deeply entrenched gender inequalities, grounded in a mix of cultural, religious and social facts inherent within patriarchal families and communities,*' is recognised internationally as a violation of the fundamental rights of women and girls and a serious form of gender-based violence[1]. Health implications of FGM are wide-ranging and well-established. Immediate health consequences include shock, haemorrhage, infection, and psychological trauma, while long-term risks include chronic pain, infections, cheloids, primary infertility, urogenital complications, birth complications, and danger to newborns[2, 3]. Though sometimes referred to as 'cutting' or 'female circumcision', this article uses 'FGM' to acknowledge the harm to women and communities.

Data indicate the existence of large communities potentially-affected by FGM in many European countries[1, 4]. For example, 23,979 people born in one of 29 'FGM-practising countries'[5], were living in Scotland in 2011[6]. However, attempts to estimate numbers of women and girls who have undergone or are at risk of FGM in diaspora communities in Europe have proven difficult due to data limitations and lack of agreement on prevalence estimation methods[4]. Additionally, the extent to which migration experiences may change attitudes and practices remains under-researched[7]. This article uses the term 'potentially-affected communities' to avoid presumptions attached to 'FGM practising communities' that may be inaccurate in a migratory context[8].

The concept of community is not straightforward, with a range of contradictory and related meanings used on all sides of the political spectrum[9]. Often defined by geography, interest, or identity, communities are not homogenous or static but rather diverse, dynamic, and multifaceted entities[10]. This article primarily describes communities of identity, where the common bond is often nationality, ethnicity, and the experience of exile, although some may also be issue-based or geographical.

FGM is described as a '*tradition in transition*'[11], with some experts asserting that empowering affected communities will lead to its elimination[7, 12, 13]. Public, media, and political attention on FGM in diaspora communities within Europe has increased, but often focuses on criminal justice and child protection[14]. While many European countries have enacted legislation and policy initiatives, the role of communities in interventions addressing FGM remains limited[1, 14]. Little research has been conducted on the role of communities in FGM interventions and very few have been rigorously evaluated[15]. Thus, community

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3 voices are generally missing from FGM policy debates and partnerships, despite growing
4 consensus that communities are key in addressing FGM[16]. Working with potentially-
5 affected communities may provide a key opportunity, as the process of migration and exile
6 allows communities to reflect, question, and debate traditional beliefs[17, 18].
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10 This study aimed to explore the role of communities within interventions to address FGM in
11 Europe, describing perspectives of practitioners, activists, and community representatives on
12 current practices, promising interventions, and gaps that should be addressed. Findings are
13 presented using the Scottish Government's 4Ps framework (i.e. prevention, protection,
14 provision of services, participation) described in its strategic approach to tackling violence
15 against women[19]. This approach reflects and builds upon European level work, e.g. the
16 European Institute for Gender Equality identifies five focus areas (i.e. prevalence, prevention,
17 protection, prosecution, provision of services) as does the Due Diligence Standard of the
18 Istanbul Convention (i.e. prevent, protect, prosecute and punish, provide services and
19 redress) that was signed by 47 countries with FGM interventions[1, 20]. Thus, themes have
20 relevance for policy-makers, researchers, community development practitioners, and
21 professionals working with potentially-affected communities.
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29 **Methods**

30 *Study design*

31 A qualitative study design was selected, drawing on data from a scoping literature review[21]
32 and interviews (i.e. individual and group) with Europe-based academics, legal professionals,
33 statutory and voluntary service providers, community activists, and representatives from
34 potentially-affected communities. The research question was "*What is the role of potentially-
35 affected diaspora communities in interventions that respond to and challenge FGM in
36 Europe?*" Table 1 provides definitions used.
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43 *Participant sampling and recruitment*

44 Individual interview participants were recruited purposively to include academics, policy-
45 makers, police officers, NGO staff, and community activists in EEA member countries with
46 recognised FGM responses. Potential participants were selected from FGM publication
47 authors and conference presenters, heads of relevant government departments and NGO
48 programmes, community activists, and snowballing from other participants. Of 27 invitees, 18
49 participated.
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54 Group interview participants were recruited purposively to include senior and mid-level
55 policy-makers, statutory and voluntary service providers, and community representatives
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3 selected for their FGM expertise and activism. Potential participants were selected from
4 managers of relevant government departments, NGOs, community organisations, and
5 activists who had worked with Scottish Refugee Council on women's rights projects. To
6 reduce barriers to participation for some community representatives, travel expenses and
7 childcare were provided. Of 59 invitees, 36 participated.
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10 11 *Data collection*

12 *In-depth key-informant interviews* were conducted by EC and HB in English and French.
13 Interviews lasted approximately 60 minutes, were audio recorded or scribed depending on
14 permission, and conducted in locations of participants' choosing.
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19 *Semi-structured group interviews* were facilitated by EC and NM in English. Discussions
20 lasted approximately 1.5 hours, included 4-9 participants, were either audio-recorded or
21 scribed, and facilitated in a central Glasgow venue.
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24 25 *Analysis and reporting*

26 Data were analysed thematically. The Scottish Government's strategic approach to
27 preventing and eradicating violence against women and girls '4Ps' framework (i.e.
28 prevention, protection, provision, participation) was used for initial deductive coding.
29 Additional themes emerged using inductive coding. EC and NM coded data using *Dedoose*
30 software, with checks by HB. Discrepancies were resolved through discussion and
31 agreement among all authors. Reporting adhered to COREQ criteria for qualitative
32 research[22].
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38 39 *Patient and public involvement*

40 As 'patient involvement' was not applicable to this study, community advocates and women
41 from potentially-affected communities acted as civil society and public representatives.
42 Development of research question and outcome measures were informed by women's
43 priorities, experience, and preferences through consultation with women's groups and review
44 of unpublished literature. Women and advocates from potentially-affected communities were
45 involved in study recruitment and conduct through the use of snowball sampling of
46 participants and review of initial findings. Results were disseminated to study participants
47 through sharing of the technical report, invitation to the report launch event, and open access
48 publication of related articles.
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54 55 *Ethics*

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3 The Research Ethics Committee of the London School of Hygiene & Tropical Medicine
4 granted ethics approval (reference 7977).
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7 **Findings**

8 Table 2 shows 18 individual interviews were conducted with participants working EU-wide
9 and/or in seven countries with active interventions addressing FGM (i.e. Belgium, England,
10 France, Ireland, Netherlands, Scotland, Spain). Five group interviews were conducted with a
11 total of 36 policy-makers, service providers, and community representatives. Community
12 participants, from Sudan, Somalia, Gambia, and Uganda, were activists or representatives of
13 voluntary or community-led organisations working to address FGM.
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19 The role of communities is reported under the four 4Ps framework themes and one emergent
20 theme (i.e. barriers to involvement). Each thematic section includes analysis of the extent to
21 which potentially-affected communities were involved in addressing FGM in Europe
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25 *Prevention*

26 The role of potentially-affected communities in prevention is described under three emergent
27 sub-themes of: (i) women's leadership; (ii) roles of men, youth, and religious leaders; and (iii)
28 effective prevention interventions.
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32 *Women's leadership:* Participants identified women from potentially-affected communities,
33 including survivors, as playing key roles in addressing FGM. Provided they had the trust and
34 respect of their communities, these '*knowledgeable cultural guides*[23] were considered
35 central to changing community behaviours. A participant explained that while '*it doesn't need*
36 *to be a survivor...you do need someone from that community*' (KIF07). Norman and
37 colleagues noted the effectiveness of messages from within communities:
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41 *'Women's arguments against FGM, spoken fluently and in their own words and*
42 *crucially, coming from within the community, provide an important resource for those*
43 *working to end FGM*[16]
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47 A UK participant highlighted the significance of a women-led '*African diaspora organisation*'
48 addressing FGM:
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50 *"People recognize that we seem to have some kind of understanding of the issues...
51 We...brought a woman from Somalia to deliver a session on social services and
52 safeguarding children. It was a different dynamic... because this is somebody from the
53 community talking about these issues."* (KIF15)
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3 *Roles of men, youth, and religious leaders:* While women from affected communities have
4 been vital in prevention interventions, participants identified the important male role that was
5 often missing.
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7 *'Something that's really missing is when we talk about the community, we always*
8 *target women, but what about the men, are they not part of the decision-making?*
9 *FGM is not only the woman's decision.'* (KIF07)
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13 Male perspectives provided deeper reflection about cultural complexities surrounding FGM
14 and the most common arguments for its continuation[24]. One participant noted that men
15 were increasingly involved and no longer viewed FGM as strictly *'women's business'* (KIF02).
16 Another participant noted that men in migratory contexts were far more likely to be involved
17 than in countries of origin (KIF09). In the Netherlands, involving men was common:
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20 *'I never heard it was difficult to involve men and the men I've spoken with are very*
21 *passionate.'* (KIF05).
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25 Participants identified young people as critical *'advocates of change'* (KIF15) and *'parents of*
26 *the next generation'* (KIF04), able to speak freely about FGM and more likely to become
27 involved in community activism. One participant noted that young people were most at risk of
28 FGM and so educating and working with young people was vital if girls were expected *'to*
29 *come forward and express their fear of having FGM'* (KIF17). Examples of effective work with
30 British young people included Daughters of Eve, Integrate Bristol, and FORWARD. In Ireland
31 and the UK, young people were involved in projects including *'using films and resources to*
32 *support [...] statutory professionals in schools'* (KIF07), and developing poetry, radio
33 documentaries, films, and music videos to *'encourage that conversation to happen in as*
34 *many different settings as you can'* (KIF04).
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41 Religious leaders influenced many communities and therefore could play a *'pivotal and*
42 *respected role'* [25]. As one participant stated, *'in our community when we are worried about*
43 *anything we contact our religious leaders'*, suggesting involvement of religious leaders could
44 be key (KIF17). Most religious leaders were men, potentially easing work with other men
45 (KIF17). However, another source noted the need *'to critically examine the added benefit'* as
46 preventative work had challenged the religious justifications of FGM without necessarily
47 involving religious leaders[25].
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53 *Effective interventions:* The World Health Organisation (WHO) recommended a shift from
54 awareness-raising to behaviour change approaches in 2009[1]. However, despite some
55 exceptions, prevention interventions focused on awareness-raising rather than
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3 empowerment and targeted behaviour change[1, 15]. Awareness-raising approaches often
4 had broad target audiences and aims rather than focusing on communities most at risk.
5 Thus, 'key targets ...may not be fully reached or engaged'[1]. Equally, approaches that
6 focused on individual change, without acknowledging community belief systems, have
7 resulted in slow progress addressing FGM across Europe[15]. When community
8 organisations and statutory professionals worked together on prevention work, using joint
9 messages on ending FGM, FGM rejection reportedly increased[25, 26].

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15 Participants identified EU-funded REPLACE and REPLACE2 programmes as effective
16 prevention interventions, focused on Belgium, England, Italy, the Netherlands, Portugal, and
17 Spain. REPLACE developed a toolkit for conducting participatory action research (PAR) with
18 communities and a behaviour change cycle framework for enabling community members to
19 take action to end FGM[15]. Enabling community members themselves to gather data from
20 within their communities ensured that 'research is conducted 'with' rather than 'on' the
21 community'[15].

25 "[REPLACE is] *innovative because it focuses on behaviour change; it works directly*
26 *with the communities, which is quite exceptional in Europe [...It is] framed in a theory of*
27 *behaviour change, which really has a thorough methodology... and also an evaluation.*"
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29 (KIF06)

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33 Participants identified PAR approaches generally as good practice, able to provide in-depth
34 understanding of the interventions needed with particular communities. Participants identified
35 a PAR initiative called Participatory Ethnographic Evaluation and Research, developed by
36 Options and Swansea University, as "*an eye opener for a lot of the community members*"
37 (KIF15) who recognised that FGM must be addressed in their community and went on to play
38 key roles in other FGM interventions.

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43 Participants described *Ketenaapak* ('Dutch Chain Approach') in the Netherlands as
44 particularly effective. This model was described as a '*meaningful initiative to involve*
45 *communities in FGM prevention work and a landmark in the prevention of FGM in the*
46 *Netherlands*[1]. In this multi-disciplinary approach, over 100 key community figures
47 contributed to child protection and prevention through organising home visits and meetings
48 within their communities to raise FGM awareness (KIF05). Several participants identified the
49 *Federation of Somali Associations in the Netherlands (FSAN)* as a grassroots organisation
50 playing an important role in identifying key figures within communities, coordinating activities,
51 and providing training (KIF02; KIF03),
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3 The Tackling FGM Initiative (TFGMI), established in the UK in 2010, was a six-year
4 collaboration between five funding bodies to strengthen community-based preventative
5 work[26]. It provided many examples of good practice focused on community-led prevention
6 and participation in activities across the UK, highlighting the crucial role of community
7 'champions' supported by community organisations[25]. For example, a Manor Gardens
8 training programme enabled London women and men to become paid Community
9 Facilitators and work with healthcare professionals to organise FGM sessions (KIF18).
10 Another example, Africa Advocacy Foundation, relied on social networks to create '*sister*
11 *circles*' (safe spaces for women) to enable community conversations around FGM in
12 Southeast London[25]. Safe, women-only spaces were considered important '*for women to*
13 *discover for themselves the nature of their reality through discussions with other women*'[27],
14 as a first step in rejecting FGM[25]. As one participant noted, '*one of the mistakes we make*
15 *is that we assume everyone knows that FGM is harmful whereas many women from*
16 *communities or women who have experienced FGM don't see that*' (KIF17).
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25 *Protection*

26 The role of potentially-affected communities in protection is described under two sub-themes
27 (i) prevention-protection linkages and (ii) effective protection.
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31 *Prevention-protection linkages:* Despite consensus that legislation and criminal justice
32 approaches helped provide an enabling framework for prevention work, participants noted
33 that such approaches could not succeed without a parallel focus on prevention.
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35 *"Given the deep-rooted cultural nature of harmful traditional practices, we can mount*
36 *as many arrests as we possibly can [...], but unless...an affected community changes*
37 *their thinking, then we're never going to truly...prevent or...eradicate these practices."*
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39 (KIM12)
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43 Prevention and protection were described by one participant as '*two sides of the same coin,*
44 *neither can succeed without the other*' (KIF14). However, there are recognised tensions
45 between these approaches[1, 28]. Preventive approaches are generally more collaborative[1]
46 and community-focused[28]. Protection approaches, whilst perhaps necessarily promoting an
47 unequivocal message around child protection, may lead to families being viewed as potential
48 perpetrators[1]. Several participants highlighted that culturally aggressive top-down
49 approaches imposed on communities, without the building of trust between families and
50 professionals, could have unwanted consequences, e.g. girls being taken abroad for FGM
51 (KIF01)[7] or already marginalised families, pushed further from mainstream society,
52 '*cling[ing] to their own cultures and traditions more tightly*'[28].
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4 Participants in France and the Netherlands reported some success in achieving attitudinal
5 change and reducing FGM through a combination of prevention and protection interventions.
6 In France, a number of high profile prosecutions and legislative measures had been
7 accompanied by investment in training and support for professionals, as well as education
8 and awareness-raising in schools and universities, though the role of communities was not
9 necessarily clear within this (KIF02). In the Netherlands (i.e. *Katenapaak*), participants
10 reported most success developing a crucial role for communities within combined prevention
11 and protection responses (KIF05). UK approaches were criticised for failing to effectively link
12 protection and prevention agendas and involve communities: “...efforts to reduce FGM have
13 focused on punitive legislation without at the same time empowering women in communities
14 to engage in debate, change attitudes and create alternative ways of affirming their cultural
15 identity”[14]. However, describing a successful Police-led community conference, a UK
16 participant suggested that this was shifting, with many organisations ‘*motivated by the need*
17 *for change*’ and prepared to support the police in developing ‘*community-driven*’ solutions
18 (KIM12).
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28 *Effective protection:* Participants highlighted community involvement in protection
29 interventions in the Netherlands, UK, and Spain. UK participants noted statutory agencies
30 involving community organisations at an earlier stage when girls were identified as at risk of
31 FGM (KIF17, KIF18). For example, FORWARD in London and NEw STep for African
32 Community (NESTAC) in Manchester worked alongside authorities to deliver family
33 education sessions, overcoming language and cultural barriers to strengthen engagement
34 (KIF18). In Bristol, social services increased the capacity of community organisations to take
35 on ‘safeguarding’ roles, working together to ensure common understandings of risk (KIF18).
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41 However, some participants expressed reservations about communities’ role in protection
42 interventions, suggesting that statutory agencies passing on risk management responsibility
43 to community organisations was risky (EG1; KIF18). Another noted that community
44 organisations with experience of case management, e.g. around violence against women or
45 asylum-seekers, could better manage the complexities of taking on a protection role[25]. A
46 participant described the value of joint-working, in building community confidence to report
47 concerns.
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51 *“If there is a cutter in the community, the chances are higher that the community*
52 *members would be aware of it than a professional...we need to work with*
53 *communities to train them and empower them...so they can report for themselves.”*
54 (KIF17)
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4 Other examples included developing tools to support protection of individual women and
5 girls. The Dutch Government produced a passport-sized declaration, signed by a range of
6 community and non-community organisations, stating that FGM is forbidden and punishable
7 by a prison sentence and loss of rights to residency, which families can carry when travelling
8 overseas (KIF05). A Spanish region produced a similar official letter for families travelling
9 abroad (KIF01). Participants highlighted the need for such tools to be developed in
10 partnership with communities, as in the Netherlands. UK participants noted that when a
11 similar tool was developed by the UK Government, communities did not feel ownership of it,
12 lessening its impact (KIF15).
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19 *Provision*

20 The role of potentially-affected communities in services provision is described under two sub-
21 themes: (i) provision roles and (ii) facilitating access.
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25 *Provision roles:* Participants identified community organisations across Europe providing
26 services from advocacy to psychological support, e.g. Daughters of Eve, FORWARD, FSAN,
27 and GAMS - the *Groupe pour l'Abolition des Mutilations Sexuelles* (KIF03; KIF06, KIF15;
28 KIF17). Fewer examples existed of community organisations influencing the planning, design
29 or delivery of services, although participants concurred on the need for this (KIF17; KIF15;
30 KIF18).
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34 *"If communities are involved they can tell what kind of services they require, rather*
35 *than...you know coming from top down, where they make assumptions."* (KIF17)
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38 *Facilitating access:* Although community organisations seldom delivered clinical services,
39 they had an important role in facilitating women's engagement *"to understand why that*
40 *service exists and... taking the time to explain it ...which is something that many health*
41 *providers don't have the time to do"* (KIF17). UK participants described community
42 involvement in developing and delivering specialist services (KIF15; KIF18). For example, an
43 FGM clinic in Bristol was developed in response to lobbying from women who were involved
44 in its design and sat on its steering group (KIF18). A London project, developed to support
45 women failing to attend specialist appointments at an FGM clinic, involved community
46 members calling/meeting clients to explain appointments, which improved services uptake
47 (KIF18).
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54 In response to such barriers as a reluctance to disclose FGM to health professionals (KIF05),
55 a fear of being criminalised (KIF17), or a lack of trust (KIF18), compounded by health
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3 providers' own discomfort and reluctance to initiate discussions around FGM[29], community
4 organisations and members were regarded as having a key role in facilitating access to
5 services. Participants identified an example of a service employing outreach workers from
6 the community who take on a 'mediating role' (KIF18). In another example, the Dutch
7 Government funded a community organisation to implement an awareness raising campaign
8 to get information to women about services available to them (KIF05). Another participant
9 described a more informal role.

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13 *"I often get people phoning me asking for advice and support... A lot of women would*
14 *say that they don't want to ask someone outside [...] So we need... a way... to give*
15 *confidence to women to be able to speak to their GP or health visitor about their fear of*
16 *FGM without feeling criminalised."* (KIF17)
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20 Many participants highlighted the gap between communities and statutory agencies and the
21 need for engagement models that facilitated improved trust, confidence, and access (KIF15;
22 KIF15; KIF18; KIF17; KIF08).
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26 *Participation*

27 The role of potentially-affected communities in participation interventions is described under
28 four sub-themes: (i) communities' vital role, (ii) engagement and representativeness, (iii)
29 involvement in campaigns, and (iv) the value of a clear and inclusive national strategy.
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34 *Vital role:* Literature and interview sources highlighted that empowering affected communities
35 was the only way to end FGM[7, 12, 13, 23]. All participants emphasised the key role of
36 potentially-affected communities, indicating it was vital to ensure interventions were informed
37 by the experiences, needs and views of those affected by FGM.
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40 *'Anything around FGM needs to be championed and developed with people affected at*
41 *the centre and leading the work.'* (CG1)
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44 Supporting and enabling community organisations to participate in policy-making was
45 identified as essential.
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47 *'Finding ways and mechanisms to give [community organisations] that capacity, the*
48 *framework and leverage for them to be heard [is] very important because I don't*
49 *believe we can effectively abandon FGM in Europe [...] if those communities are not*
50 *the ones...acting for the abandonment of FGM. It's a very important role and only they*
51 *can actually do it.'* (KIF10)
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3 *Engagement and representativeness:* Despite consensus on its value, most participants said
4 insufficient efforts were made by policy-makers and practitioners to engage with communities
5 (KIF06; KIF01; KIF07; KIF17; KIF18). This was particularly evident in the UK, with existing
6 approaches described as *'piecemeal'* (KIF15) and *'tokenistic'* (KIF17; KIF18). Community
7 participants cited examples of being excluded or included at the last minute to *'tick a box'*
8 (KIF17) or when statutory professionals had a crisis (KIF18). In contrast, engagement in the
9 Netherlands was described as *'active'* (KIF05; KIF18).

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13 *'I don't think there's any such thing as a hard-to-reach group. I think there's*
14 *something called 'failed-to-reach groups by the statutory agencies' because there'll*
15 *always be individuals or an organisation who'll get you access to affected*
16 *communities.'* (KIM12)

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20 Participants noted a tendency of UK decision-makers to engage with the same handful of
21 individuals as *'leaders'* or *'spokespeople'* (KIF18). One highlighted the difference between
22 enabling individual community members to participate and working with community
23 organisations.
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26 *"[Community organisations] are bringing more than just their personal opinion, they*
27 *tend... to be engaging more widely with the community and so can be a channel to*
28 *have these voices heard."* (KIF18)

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32 Representativeness appeared to be a particular challenge for countries newer to FGM issues
33 (e.g. Portugal) as community organisations might not yet exist around this issue or have
34 confidence and advocacy experience (KIF18). Thus, whether effective or *'active'* participation
35 was achieved appeared to vary between - and sometimes within – countries, potentially
36 depending on whether decision-makers valued community organisations.
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39 *"It depends... whether the local authority [...] values community interventions and*
40 *whether they see the community as a problem and... statutory professionals as the*
41 *answer...or whether [the local authority] views the community as part and parcel of*
42 *[...] the solution."* (KIF18)

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47 UK participants noted that most FGM work occurred in silos, further challenging effective
48 participation. Interventions focused solely on FGM failed to account for *'gendered social*
49 *norms... and nature of women's lives'* (KIF15)[30]. Participants indicated that separating
50 FGM from issues like domestic violence was a major problem.
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53 *"They are seen as completely separate topics or discrete topics as opposed to how*
54 *do these principles cut across the way we navigate our communities and navigate our*
55 *spaces."* (KIF18)

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4 *Campaigns:* Several participants said that communities played an important role in
5 campaigning and awareness-raising. The Europe-wide End FGM Campaign led by Amnesty
6 International Ireland and the lobbying work of GAMS, a large French NGO founded in 1982
7 by women of African and Western origin, were highlighted (KIF02). Others spoke of the
8 important work of high profile survivor-campaigners, such as Layla Hussein in the UK
9 (KIF07). One participant talked about her own role as a community campaigner in '*raising*
10 *awareness through fashion...music and culture nights*' and '*campaigning, lobbying and*
11 *working with the government*' (KIF07).
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18 *Strategy:* Several participants noted that addressing FGM required strong strategic
19 frameworks. Most suggested this should be a resourced, standalone, multi-agency, national
20 action plan, developed in partnership with key stakeholders, including affected communities:
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22 *"Authorities should... design a plan of action on FGM and...attach a budget to it and [it]*
23 *should not only be developed by officials in their offices but in collaboration with the*
24 *communities themselves and with all stakeholders."* (KIF06)
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28 At least eight European countries had developed national FGM action plans by 2013[1] and
29 Scotland did so in 2016[31]. There were very few examples across Europe of communities
30 having a role in strategy development or being supported to influence policy and practice.
31 The Finnish National Action Plan provided an example of community engagement, as it was
32 developed by a working group of government ministries and African women's
33 organisations[1]. Scotland's national action plan incorporated clear actions on community
34 participation, but participants noted limited engagement with communities in its development
35 (KIF17) and a general absence of community voices in the policy arena in Scotland (CG1;
36 CG2; KIF17). Participants in several European countries noted disconnects between policy
37 and reality.
38

39 *"One thing we're missing which is the reality for many European countries, is the*
40 *grassroots... There's a lot of awareness and there's a lot of policy but somehow we don't*
41 *understand what's happening at the grass roots."* (KIF07)
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49 ***Barriers to community participation***

50 The main barriers identified to effective work with communities were: (i) cultural, i.e. within
51 communities; (ii) structural, i.e. external to communities; and (iii) sustainability-related.
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54 *Cultural:* Leadership of FGM work is not easy and participants described the importance of
55 supporting community-members taking on such roles, e.g. through training, information, and
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3 access to services (KIF05; KIF13; KIF13). Negative consequences for community leaders or
4 activists have been documented[32], including verbal abuse, criticism, threats, and family
5 conflict (KIF05; KIF04; KIF17).
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7 *“I’ve had people from my community who have sent me...hate messages, saying...
8 what you’re doing is wrong. And I’ve had family-members who have said that they
9 will no longer speak to me... and that I... bring shame on them. It’s not... easy for me
10 to take on this role. Trust me, there were times when I almost gave up” (KIF17)*
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14 Women may worry about bringing shame on their communities or experience shame or guilt
15 if they speak about FGM to service providers or other ‘outsiders’ (KIF17; KIF16)[33],
16 particularly as some communities are explicitly told not to speak about FGM (KIF17). Trust-
17 related barriers were thus common between communities and professionals (KIF07; KIF04),
18 particularly within child protection (KIF18) or health services, where usage of interpreters
19 could compound trust issues (KIF16; KIF17). Taking time to build trust was therefore deemed
20 important
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25 *‘It’s not a case of turning up with knowledge, but of starting off with the knowledge of
26 communities themselves, then building something together’ (KIF02)*
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29 Gender norms and power dynamics within potentially-affected communities were identified
30 as potential barriers, with several participants highlighting the importance of working with
31 men and women separately before bringing them together if appropriate (KIF04; KIF07).
32 While gender oppression was a structural barrier experienced by women globally, “*its
33 manifestation differs according to culture, country and social grouping*”[27], thus affecting
34 which avenues were open to women to challenge or engage with FGM and other aspects of
35 their lives[30, 34].
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41 *Structural:* Lack of understanding among professionals of the value and potential role of
42 communities was highlighted as a key barrier to their involvement in interventions. Key
43 decision-makers and service providers would need to change the ways in which they work to
44 ensure that communities were actively involved and heard. One participant provided an
45 example of statutory professionals in Bristol who developed alternative ways of engaging
46 with communities including attending community events, holding informal consultations, and
47 making meetings and meeting space more equitable and community friendly (KIF18). Lack of
48 compensation for travel and childcare expenses was cited as a barrier by several
49 participants, including a lack of understanding by some professionals of why such expenses
50 would even be required (KIF06; KIF17; KIF18).
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56 *‘It still feels like there is a need to explain the added value of communities to the*
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3 *powers that be.'* (KIF18)
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6 *Sustainability:* Participants in different contexts raised concerns about the sustainability of
7 FGM interventions, particularly those at community level that required long-term investment.
8 Some indicated that although community-led organisations were often approached for their
9 expertise, they were rarely funded for this advisory role (KIF15) and that significant
10 government funding was needed (KIF06; KIF15). Others highlighted the need for longer-term
11 investment in implementation and action beyond developing protocols, frame-works, and
12 action plans (KIF15; KIF03). Several noted that much of the work of community organisations
13 was not financially valued, with one participant stressing how important it was to recognise
14 the challenging nature of this work, which is '*under-valued and under-resourced*', and
15 questioning how long community members could continue to volunteer in such challenging
16 roles (KIF15).
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23 **Discussion**

24 *Principle findings*

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26 Clear consensus emerged that potentially-affected communities should have a role in all
27 intervention areas and that this was vital to addressing FGM in Europe[1, 15, 25]. Despite
28 this consensus and several examples of good practice (e.g. EU-funded REPLACE and
29 REPLACE 2 programmes, Dutch *Ketenaapak*, the Tackling FGM Initiative), community roles
30 remained inconsistent in FGM interventions and often non-existent in FGM policy
31 development.
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37 Practices ranged from good examples of support for community-led interventions and
38 partnership work with communities to less positive examples of tokenism and non-
39 participation. Most FGM interventions across Europe focused on awareness-raising, and
40 despite examples of good practice noted above, community participation appeared fairly
41 minimal[1, 15]. The extent of community participation was inconsistent between and within
42 countries. While community participation was accepted as vital, participants noted that
43 practices associated with community participation varied enormously. This corresponded
44 with the significant literature highlighting challenges inherent in increasing community
45 participation, e.g. what level of participation[35, 36], '*who participates, in what, and for whose*
46 *benefit*[37], and to what extent government organisations that engage with communities
47 could change to develop truly participatory processes and spaces[38].
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55 The role of communities appeared most developed within prevention interventions, with good
56 practice examples of both community-led initiatives and partnership. Protection-focused
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3 approaches were more challenging in terms of participation, as the clear child-protection
4 focus could stigmatise families[1, 7]. Community participation within safeguarding varied,
5 with examples of both effective and emerging roles. Individuals and organisations had roles
6 in building trust and bridging gaps between communities and authorities, though
7 responsibility for managing risk should remain firmly with statutory bodies[25]. While several
8 community-led organisations delivered a range of services, few examples were found of
9 communities participating in designing, delivering or evaluating statutory services. Good
10 practice examples were identified of community organisations or activists playing a key role
11 in facilitating services access and enabling dialogue within communities to occur[25].
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16 17 *Implications for policy and practice*

18 Engaging potentially-affected communities in coordinated multi-agency responses appears
19 critical to the success of FGM policies and interventions in Europe. Decision-makers and
20 service providers should invest in community engagement by (i) ensuring that community
21 organisations can participate actively in future interventions and (ii) addressing cultural,
22 structural, and sustainability-related barriers to participation.
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28 Supporting and strengthening community organisations can improve engagement. Bottom-up
29 approaches that enable dialogue within communities appear most successful. Community
30 development support could enable potentially-affected communities to identify their own
31 FGM-related concerns and aspirations and work collectively to identify solutions and take
32 action. This requires long-term investment in community development support and
33 community organisations themselves, to support community-led interventions and
34 meaningful engagement between communities and policy-makers. Any engagement with
35 communities must begin with identifying those communities potentially affected,
36 acknowledging that communities are not homogenous, and engaging with a wide range of
37 groups and community representatives across nationalities and ethnicities. As most women
38 and girls affected by FGM also identify as people of colour, perspectives and lived
39 experiences must be included in development of meaningful policies and services.
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47 Research on FGM interventions across Europe is limited, when compared to levels of
48 activism. Research has focused on clinical care, provision of health services, and attitudes
49 towards FGM. Minimal investigation has been conducted on the role of diaspora
50 communities and their contributions to challenging and responding to FGM. Empowerment,
51 engagement, and participation are frequently mentioned, but rarely critically examined, with
52 little discussion about how to move beyond rhetoric towards putting these concepts into
53 practice. Further research with communities, including participatory methods, appears
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3 warranted. Any such research should include the voices of affected women and girls, as
4 those best able to describe their lived experiences and needs and to contribute to the
5 additionally sensitive topics of prosecution and redress.
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8 *Limitations*

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10 This study had three significant limitations. First, this study was exploratory and participant
11 numbers were limited due to time and resource constraints. Second, numbers of participants
12 from potentially-affected communities were limited and further community engagement is
13 needed to expand on issues raised. Finally, focus on European interventions ignored the
14 successfully designed and implemented African interventions, e.g. TOSTAN
15 (www.tostan.org) that offer international benchmarks for changing attitudes and reducing
16 FGM[21].
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22 **Conclusion**

23 Exploring the role of communities within interventions to address FGM in Europe allowed
24 critical examination of how crucial community voices remain marginalised and could be
25 better heard and supported. “*Without an effective commitment to the participation and*
26 *empowerment of potentially-affected communities, policy-makers and practitioners will not*
27 *identify the actual risks experienced by diaspora girls and women in Europe or develop*
28 *effective interventions, and risk further marginalising those community voices that are the*
29 *most effective advocates for change*”[6]. Results demonstrate that it is possible to work
30 alongside potentially-affected communities, benefitting from community perspectives and
31 expertise, to develop meaningful partnerships and support community-led interventions.
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38 **Declarations**

39 *Conflict of interest*

40 None declared.
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43

44 *Author contributions*

45 EC contributed to study design, data collection and analysis and drafted the manuscript. NM
46 contributed to study design, data analysis, and manuscript writing. HB contributed to study
47 design, data collection and analysis, and critically reviewed the manuscript. NH contributed
48 to study design and data interpretation and critically revised the manuscript. All authors
49 approved the version for submission.
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54 *Acknowledgements*

55 Special thanks to all key informants, particularly women from potentially-affected
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3 communities, for their invaluable insights.

4 5 6 *Funding*

7 This work was supported by the Scottish Government Equality Fund and Rosa FGM Small
8 Grants Programme for funding research.
9

10 11 12 *Data sharing*

13 Anonymised dataset and coding are available on request in accordance with LSHTM
14 institutional data management policy.
15

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For peer review only

Tables

Table 1. Key definitions

Female genital mutilation	All procedures that involve partial or total removal of the female external genitalia, or other injury to the female genital organs for non-medical reasons (WHO, 2016)
Community	A community of identity has a common bond based on ' <i>geography, identity or interest</i> ' [10]
Community development	Community development enables people to work collectively to bring about positive social change. This long-term process starts from people's own experience and enables communities to work together to: <ul style="list-style-type: none"> • identify their own needs and actions; • take collective action using their strengths and resources; • develop their confidence, skills and knowledge; • challenge unequal power relationships; • promote social justice, equality and inclusion; to improve the quality of their own lives, the communities in which they live and societies of which they are a part [10]
Participation	Policy-making and practice development around violence against women is shaped by the experiences, needs and views of those affected by FGM [6]
Potentially-affected community	A diaspora community from one of 29 countries identified by UNICEF, in which FGM practices are concentrated, i.e. Somalia 98%, Guinea 96%, Djibouti 93%, Egypt 91%, Eritrea 89%, Mali 89%, Sierra Leone 88%, Sudan 88%, Gambia 76%, Burkina Faso 76%, Ethiopia 74%, Mauritania 69%, Liberia 66%, Guinea-Bissau 50%, Chad 44%, Cote d'Ivoire 38%, Kenya 27%, Nigeria 27%, Senegal 26%, CAR 24%, Yemen 23%, Tanzania 15%, Benin 13%, Iraq 8%, Ghana 4%, Togo 4%, Niger 2%, Cameroon 1%, Uganda 1% [5, 39]
Prevention	Interventions intended to create and/or sustain behavioural and attitudinal change within affected communities [6]
Protection	Interventions intended to protect the individual rights of women and girls who are at risk of or have experienced FGM [6]
Service provision	Service responses to survivors of FGM [6]

Table 2. Participant characteristics

ID	Role/Title	Location	Interview type
KIF01	University professor	Spain (Skype)	KII
KIF02	NGO worker	France	KII
KIF03	NGO worker	Netherlands	KII
KIF04	Teacher	England	KII
KIF05	Government minister	Netherlands	KII
KIF06	University professor	Belgium	KII
KIF07	Community activist	Ireland (Skype)	KII
KIF08	Medical professional	England	KII
KIF09	University professor	France	KII
KIF10	INGO worker	EU	KII
KIF11	Solicitor	Scotland	KII
KIM12	Police officer	England	KII
KIF13	Police officer	England	KII
KIF14	Legal professional	France	KII (unrecorded)
KIF15	NGO worker	England	KII
KIF16	Medical professional	Scotland	KII
KIF17	Community activist	Scotland	KII
KIF18	Community activist	Scotland	KII
EG1	9 policy/practice participants	Scotland	Group interview
EG2	9 policy/practice/community participants	Scotland	Group interview
EG3	10 policy/practice/community participants	Scotland	Group interview
CG1	4 community activists	Scotland	Group interview
CG2	4 community activists	Scotland	Group interview

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3 **Missing from the debate? A qualitative study exploring the role of communities within**
4 **interventions to address female genital mutilation in Europe**
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26 **Key words**
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28 FGM, female genital cutting, community development, Europe
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Abstract

Introduction

Public attention on female genital mutilation in diaspora communities is increasing in Europe, as health and social welfare implications become better understood. This study explored the role of potentially-affected communities within interventions to address female genital mutilation in Europe, **examining current practices, promising interventions, and remaining gaps.**

Methods

A qualitative study design incorporated 18 individual key informant interviews and five semi-structured group interviews with policy-makers, service providers, and community representatives. Data were analysed thematically, guided by the Scottish Government '4Ps' framework for addressing violence against women and girls, i.e. prevention, protection, provision of services, **and participation.**

Results

Participants emphasised both the importance of community participation and the lack of consistent engagement by policy-makers and practitioners. All indicated that communities had a key role, though **most** interventions focussed on awareness-raising rather than community empowerment, behaviour change, or influence on the design, delivery, and/or evaluation of interventions.

Conclusions

Despite clear consensus around the need to engage, support, and empower potentially-affected communities and several examples of meaningful community participation in addressing female genital mutilation (**e.g. REPLACE, REPLACE 2, Ketenaapak, Tackling FGM Initiative**), the role of communities remains inconsistent and further engagement efforts are necessary.

Strengths and limitations

- This study was exploratory and participant numbers were limited, including members of potentially-affected communities, due to time and resource constraints.
- Study focus was on European interventions, thus excluding many innovative and successful African interventions.
- Nevertheless, this study is a rare effort to examine the under-researched role of diaspora communities in initiatives to address female genital mutilation in Europe, drawing from in-depth and semi-structured key informant interviews.

Introduction

Female genital mutilation (FGM), a practice, defined in Table 1, that expresses '*deeply entrenched gender inequalities, grounded in a mix of cultural, religious and social facts inherent within patriarchal families and communities,*' is recognised internationally as a violation of the fundamental rights of women and girls and a serious form of gender-based violence[1]. Health implications of FGM are wide-ranging and well-established. Immediate health consequences include shock, haemorrhage, infection, and psychological trauma, while long-term risks include chronic pain, infections, cheloids, primary infertility, urogenital complications, birth complications, and danger to newborns[2, 3]. Though sometimes referred to as 'cutting' or 'female circumcision', this article uses 'FGM' to acknowledge the harm to women and communities.

Data indicate the existence of large communities potentially-affected by FGM in many European countries[1, 4]. For example, 23,979 people born in one of 29 'FGM-practising countries'[5], were living in Scotland in 2011[6]. However, attempts to estimate numbers of women and girls who have undergone or are at risk of FGM in diaspora communities in Europe have proven difficult due to data limitations and lack of agreement on prevalence estimation methods[4]. Additionally, the extent to which migration experiences may change attitudes and practices remains under-researched[7]. This article uses the term 'potentially-affected communities' to avoid presumptions attached to 'FGM practising communities' that may be inaccurate in a migratory context[8].

The concept of community is not straightforward, with a range of contradictory and related meanings used on all sides of the political spectrum[9]. Often defined by geography, interest, or identity, communities are not homogenous or static but rather diverse, dynamic, and multifaceted entities[10]. This article primarily describes communities of identity, where the common bond is often nationality, ethnicity, and the experience of exile, although some may also be issue-based or geographical.

FGM is described as a '*tradition in transition*'[11], with some experts asserting that empowering affected communities will lead to its elimination[7, 12, 13]. Public, media, and political attention on FGM in diaspora communities within Europe has increased, but often focuses on criminal justice and child protection[14]. While many European countries have enacted legislation and policy initiatives, the role of communities in interventions addressing FGM remains limited[1, 14]. Little research has been conducted on the role of communities in FGM interventions and very few have been rigorously evaluated[15]. Thus, community

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3 voices are generally missing from FGM policy debates and partnerships, despite growing
4 consensus that communities are key in addressing FGM[16]. Working with potentially-
5 affected communities may provide a key opportunity, as the process of migration and exile
6 allows communities to reflect, question, and debate traditional beliefs[17, 18].
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10 This study aimed to explore the role of communities within interventions to address FGM in
11 Europe, describing perspectives of practitioners, activists, and community representatives on
12 current practices, promising interventions, and gaps that should be addressed. Findings are
13 presented using the Scottish Government's 4Ps framework (i.e. prevention, protection,
14 provision of services, participation) described in its strategic approach to tackling violence
15 against women[19]. This approach reflects and builds upon European level work, e.g. the
16 European Institute for Gender Equality identifies five focus areas (i.e. prevalence, prevention,
17 protection, prosecution, provision of services) as does the Due Diligence Standard of the
18 Istanbul Convention (i.e. prevent, protect, prosecute and punish, provide services and
19 redress) that was signed by 47 countries with FGM interventions[1, 20]. Thus, themes have
20 relevance for policy-makers, researchers, community development practitioners, and
21 professionals working with potentially-affected communities.
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29 **Methods**

30 *Study design*

31 A qualitative study design was selected, drawing on data from a scoping literature review[21]
32 and interviews (i.e. individual and group) with Europe-based academics, legal professionals,
33 statutory and voluntary service providers, community activists, and representatives from
34 potentially-affected communities. The research question was "*What is the role of potentially-
35 affected diaspora communities in interventions that respond to and challenge FGM in
36 Europe?*" Table 1 provides definitions used.
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43 *Participant sampling and recruitment*

44 Individual interview participants were recruited purposively to include academics, policy-
45 makers, police officers, NGO staff, and community activists in EEA member countries with
46 recognised FGM responses. Potential participants were selected from FGM publication
47 authors and conference presenters, heads of relevant government departments and NGO
48 programmes, community activists, and snowballing from other participants. Of 27 invitees, 18
49 participated.
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54 Group interview participants were recruited purposively to include senior and mid-level
55 policy-makers, statutory and voluntary service providers, and community representatives
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3 selected for their FGM expertise and activism. Potential participants were selected from
4 managers of relevant government departments, NGOs, community organisations, and
5 activists who had worked with Scottish Refugee Council on women's rights projects. To
6 reduce barriers to participation for some community representatives, travel expenses and
7 childcare were provided. Of 59 invitees, 36 participated.
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10 11 *Data collection*

12 *In-depth key-informant interviews* were conducted by EC and HB in English and French.
13 Interviews lasted approximately 60 minutes, were audio recorded or scribed depending on
14 permission, and conducted in locations of participants' choosing.
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19 *Semi-structured group interviews* were facilitated by EC and NM in English. Discussions
20 lasted approximately 1.5 hours, included 4-9 participants, were either audio-recorded or
21 scribed, and facilitated in a central Glasgow venue.
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25 *Analysis and reporting*

26 Data were analysed thematically. The Scottish Government's strategic approach to
27 preventing and eradicating violence against women and girls '4Ps' framework (i.e.
28 prevention, protection, provision, participation) was used for initial deductive coding.
29 Additional themes emerged using inductive coding. EC and NM coded data using Dedoose
30 software, with checks by HB. Discrepancies were resolved through discussion and
31 agreement among all authors. Reporting adhered to COREQ criteria for qualitative
32 research[22].
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38 *Patient and public involvement*

39 As 'patient involvement' was not applicable to this study, community advocates and women
40 from potentially-affected communities acted as civil society and public representatives.
41 Development of research question and outcome measures were informed by women's
42 priorities, experience, and preferences through consultation with women's groups and review
43 of unpublished literature. Women and advocates from potentially-affected communities were
44 involved in study recruitment and conduct through the use of snowball sampling of
45 participants and review of initial findings. Results were disseminated to study participants
46 through sharing of the technical report, invitation to the report launch event, and open access
47 publication of related articles.
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54 *Ethics*

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3 The Research Ethics Committee of the London School of Hygiene & Tropical Medicine
4 granted ethics approval (reference 7977).
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7 Findings

8 Table 2 shows 18 individual interviews were conducted with participants working EU-wide
9 and/or in seven countries with active interventions addressing FGM (i.e. Belgium, England,
10 France, Ireland, Netherlands, Scotland, Spain). Five group interviews were conducted with a
11 total of 36 policy-makers, service providers, and community representatives. Community
12 participants, from Sudan, Somalia, Gambia, and Uganda, were activists or representatives of
13 voluntary or community-led organisations working to address FGM.
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19 The role of communities is reported under the four 4Ps framework themes and one emergent
20 theme (i.e. barriers to involvement). Each thematic section includes analysis of the extent to
21 which potentially-affected communities were involved in addressing FGM in Europe
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25 Prevention

26 The role of potentially-affected communities in prevention is described under three emergent
27 sub-themes of: (i) women's leadership; (ii) roles of men, youth, and religious leaders; and (iii)
28 effective prevention interventions.
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32 *Women's leadership:* Participants identified women from potentially-affected communities,
33 including survivors, as playing key roles in addressing FGM. Provided they had the trust and
34 respect of their communities, these '*knowledgeable cultural guides*[23] were considered
35 central to changing community behaviours. A participant explained that while '*it doesn't need*
36 *to be a survivor...you do need someone from that community*' (KIF07). Norman and
37 colleagues noted the effectiveness of messages from within communities:
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41 *'Women's arguments against FGM, spoken fluently and in their own words and*
42 *crucially, coming from within the community, provide an important resource for those*
43 *working to end FGM*[16]
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47 A UK participant highlighted the significance of a women-led '*African diaspora organisation*'
48 addressing FGM:
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50 *"People recognize that we seem to have some kind of understanding of the issues...
51 We...brought a woman from Somalia to deliver a session on social services and
52 safeguarding children. It was a different dynamic... because this is somebody from the
53 community talking about these issues."* (KIF15)
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3 *Roles of men, youth, and religious leaders:* While women from affected communities have
4 been vital in prevention interventions, participants identified the important male role that was
5 often missing.
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7 *'Something that's really missing is when we talk about the community, we always*
8 *target women, but what about the men, are they not part of the decision-making?*
9 *FGM is not only the woman's decision.'* (KIF07)
10
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13 Male perspectives provided deeper reflection about cultural complexities surrounding FGM
14 and the most common arguments for its **continuation**[24]. One participant noted that men
15 were increasingly involved and no longer viewed FGM as strictly '*women's business*' (KIF02).
16 Another participant noted that men in migratory contexts were far more likely to be involved
17 than in countries of origin (KIF09). In the Netherlands, involving men was common:
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20 *'I never heard it was difficult to involve men and the men I've spoken with are very*
21 *passionate.'* (KIF05).
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25 Participants identified young people as critical '*advocates of change*' (KIF15) and '*parents of*
26 *the next generation*' (KIF04), able to speak freely about FGM and more likely to become
27 involved in community activism. One participant noted that young people were most at risk of
28 FGM and so educating and working with young people was vital if girls were expected '*to*
29 *come forward and express their fear of having FGM*' (KIF17). Examples of effective work with
30 British young people included Daughters of Eve, Integrate Bristol, and FORWARD. In Ireland
31 and the UK, young people were involved in projects including '*using films and resources to*
32 *support [...] statutory professionals in schools*' (KIF07), and developing poetry, radio
33 documentaries, films, and music videos to '*encourage that conversation to happen in as*
34 *many different settings as you can*' (KIF04).
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41 Religious leaders influenced many communities and therefore could play a '*pivotal and*
42 *respected role*' [25]. As one participant stated, '*in our community when we are worried about*
43 *anything we contact our religious leaders*', suggesting involvement of religious leaders could
44 be key (KIF17). Most religious leaders were men, potentially easing work with other men
45 (KIF17). However, another source noted the need '*to critically examine the added benefit*' as
46 preventative work had challenged the religious justifications of FGM without necessarily
47 involving religious leaders[25].
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53 *Effective interventions:* The World Health Organisation (WHO) recommended a shift from
54 awareness-raising to behaviour change approaches in 2009[1]. However, despite some
55 exceptions, prevention interventions focused on awareness-raising rather than
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2 empowerment and targeted behaviour change[1, 15]. Awareness-raising approaches often
3 had broad target audiences and aims rather than focusing on communities most at risk.
4 Thus, 'key targets ...may not be fully reached or engaged'[1]. Equally, approaches that
5 focused on individual change, without acknowledging community belief systems, have
6 resulted in slow progress addressing FGM across Europe[15]. When community
7 organisations and statutory professionals worked together on prevention work, using joint
8 messages on ending FGM, FGM rejection reportedly increased[25, 26].
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14 Participants identified EU-funded REPLACE and REPLACE2 programmes as effective
15 prevention interventions, focused on Belgium, England, Italy, the Netherlands, Portugal, and
16 Spain. REPLACE developed a toolkit for conducting participatory action research (PAR) with
17 communities and a behaviour change cycle framework for enabling community members to
18 take action to end FGM[15]. Enabling community members themselves to gather data from
19 within their communities ensured that 'research is conducted 'with' rather than 'on' the
20 community'[15].
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25 "[REPLACE is] *innovative because it focuses on behaviour change; it works directly*
26 *with the communities, which is quite exceptional in Europe [...It is] framed in a theory of*
27 *behaviour change, which really has a thorough methodology... and also an evaluation.*"
28 (KIF06)
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32 Participants identified PAR approaches generally as good practice, able to provide in-depth
33 understanding of the interventions needed with particular communities. Participants identified
34 a PAR initiative called Participatory Ethnographic Evaluation and Research, developed by
35 Options and Swansea University, as "*an eye opener for a lot of the community members*"
36 (KIF15) who recognised that FGM must be addressed in their community and went on to play
37 key roles in other FGM interventions.
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43 Participants described *Ketenaapak* ('Dutch Chain Approach') in the Netherlands as
44 particularly effective. This model was described as a '*meaningful initiative to involve*
45 *communities in FGM prevention work and a landmark in the prevention of FGM in the*
46 *Netherlands*[1]. In this multi-disciplinary approach, over 100 key community figures
47 contributed to child protection and prevention through organising home visits and meetings
48 within their communities to raise FGM awareness (KIF05). Several participants identified the
49 *Federation of Somali Associations in the Netherlands (FSAN)* as a grassroots organisation
50 playing an important role in identifying key figures within communities, coordinating activities,
51 and providing training (KIF02; KIF03),
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3 The Tackling FGM Initiative (TFGMI), established in the UK in 2010, was a six-year
4 collaboration between five funding bodies to strengthen community-based preventative
5 work[26]. It provided many examples of good practice focused on community-led prevention
6 and participation in activities across the UK, highlighting the crucial role of community
7 'champions' supported by community organisations[25]. For example, a Manor Gardens
8 training programme enabled London women and men to become paid Community
9 Facilitators and work with healthcare professionals to organise FGM sessions (KIF18).
10 Another example, Africa Advocacy Foundation, relied on social networks to create 'sister
11 circles' (safe spaces for women) to enable community conversations around FGM in
12 Southeast London[25]. Safe, women-only spaces were considered important '*for women to
13 discover for themselves the nature of their reality through discussions with other women*'[27],
14 as a first step in rejecting FGM[25]. As one participant noted, '*one of the mistakes we make
15 is that we assume everyone knows that FGM is harmful whereas many women from
16 communities or women who have experienced FGM don't see that*' (KIF17).
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24 25 Protection

26 The role of potentially-affected communities in protection is described under two sub-themes
27 (i) prevention-protection linkages and (ii) effective protection.
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31 *Prevention-protection linkages:* Despite consensus that legislation and criminal justice
32 approaches helped provide an enabling framework for prevention work, participants noted
33 that such approaches could not succeed without a parallel focus on prevention.
34

35 "*Given the deep-rooted cultural nature of harmful traditional practices, we can mount
36 as many arrests as we possibly can [...], but unless...an affected community changes
37 their thinking, then we're never going to truly...prevent or...eradicate these practices.*"
38
39 (KIM12)
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43 Prevention and protection were described by one participant as '*two sides of the same coin,
44 neither can succeed without the other*' (KIF14). However, there are recognised tensions
45 between these approaches[1, 28]. Preventive approaches are generally more collaborative[1]
46 and community-focused[28]. Protection approaches, whilst perhaps necessarily promoting an
47 unequivocal message around child protection, may lead to families being viewed as potential
48 perpetrators[1]. Several participants highlighted that culturally aggressive top-down
49 approaches imposed on communities, without the building of trust between families and
50 professionals, could have unwanted consequences, e.g. girls being taken abroad for FGM
51 (KIF01)[7] or already marginalised families, pushed further from mainstream society,
52 '*cling[ing] to their own cultures and traditions more tightly*'[28].
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4 Participants in France and the Netherlands reported some success in achieving attitudinal
5 change and reducing FGM through a combination of prevention and protection interventions.
6 In France, a number of high profile prosecutions and legislative measures had been
7 accompanied by investment in training and support for professionals, as well as education
8 and awareness-raising in schools and universities, though the role of communities was not
9 necessarily clear within this (KIF02). In the Netherlands (i.e. *Katenapaak*), participants
10 reported most success developing a crucial role for communities within combined prevention
11 and protection responses (KIF05). UK approaches were criticised for failing to effectively link
12 protection and prevention agendas and involve communities: “...efforts to reduce FGM have
13 focused on punitive legislation without at the same time empowering women in communities
14 to engage in debate, change attitudes and create alternative ways of affirming their cultural
15 identity”[14]. However, describing a successful Police-led community conference, a UK
16 participant suggested that this was shifting, with many organisations ‘*motivated by the need*
17 *for change*’ and prepared to support the police in developing ‘*community-driven*’ solutions
18 (KIM12).
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28 *Effective protection:* Participants highlighted community involvement in protection
29 interventions in the Netherlands, UK, and Spain. UK participants noted statutory agencies
30 involving community organisations at an earlier stage when girls were identified as at risk of
31 FGM (KIF17, KIF18). For example, FORWARD in London and NEw STep for African
32 Community (NESTAC) in Manchester worked alongside authorities to deliver family
33 education sessions, overcoming language and cultural barriers to strengthen engagement
34 (KIF18). In Bristol, social services increased the capacity of community organisations to take
35 on ‘safeguarding’ roles, working together to ensure common understandings of risk (KIF18).
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41 However, some participants expressed reservations about communities’ role in protection
42 interventions, suggesting that statutory agencies passing on risk management responsibility
43 to community organisations was risky (EG1; KIF18). Another noted that community
44 organisations with experience of case management, e.g. around violence against women or
45 asylum-seekers, could better manage the complexities of taking on a protection role[25]. A
46 participant described the value of joint-working, in building community confidence to report
47 concerns.
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51 *“If there is a cutter in the community, the chances are higher that the community*
52 *members would be aware of it than a professional...we need to work with*
53 *communities to train them and empower them...so they can report for themselves.”*
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55 (KIF17)
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4 Other examples included developing tools to support protection of individual women and
5 girls. The Dutch Government produced a passport-sized declaration, signed by a range of
6 community and non-community organisations, stating that FGM is forbidden and punishable
7 by a prison sentence and loss of rights to residency, which families can carry when travelling
8 overseas (KIF05). A Spanish region produced a similar official letter for families travelling
9 abroad (KIF01). Participants highlighted the need for such tools to be developed in
10 partnership with communities, as in the Netherlands. UK participants noted that when a
11 similar tool was developed by the UK Government, communities did not feel ownership of it,
12 lessening its impact (KIF15).
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19 *Provision*

20 **The role of potentially-affected communities in** services provision **is described under two** sub-
21 themes: (i) provision roles and (ii) facilitating access.
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25 *Provision roles:* Participants identified community organisations across Europe providing
26 services from advocacy to psychological support, e.g. Daughters of Eve, FORWARD, FSAN,
27 and GAMS - the *Groupe pour l'Abolition des Mutilations Sexuelles* (KIF03; KIF06, KIF15;
28 KIF17). Fewer examples existed of community organisations influencing the planning, design
29 or delivery of services, although participants concurred on the need for this (KIF17; KIF15;
30 KIF18).
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34 *"If communities are involved they can tell what kind of services they require, rather*
35 *than...you know coming from top down, where they make assumptions."* (KIF17)
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38 *Facilitating access:* Although community organisations seldom delivered clinical services,
39 they had an important role in facilitating women's engagement *"to understand why that*
40 *service exists and... taking the time to explain it ...which is something that many health*
41 *providers don't have the time to do"* (KIF17). UK participants described community
42 involvement in developing and delivering specialist services (KIF15; KIF18). For example, an
43 FGM clinic in Bristol was developed in response to lobbying from women who were involved
44 in its design and sat on its steering group (KIF18). A London project, developed to support
45 women failing to attend specialist appointments at an FGM clinic, involved community
46 members calling/meeting clients to explain appointments, which improved services uptake
47 (KIF18).
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54 In response to such barriers as a reluctance to disclose FGM to health professionals (KIF05),
55 a fear of being criminalised (KIF17), or a lack of trust (KIF18), compounded by health
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3 providers' own discomfort and reluctance to initiate discussions around FGM[29], community
4 organisations and members were regarded as having a key role in facilitating access to
5 services. Participants identified an example of a service employing outreach workers from
6 the community who take on a 'mediating role' (KIF18). In another example, the Dutch
7 Government funded a community organisation to implement an awareness raising campaign
8 to get information to women about services available to them (KIF05). Another participant
9 described a more informal role.

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13 *"I often get people phoning me asking for advice and support... A lot of women would*
14 *say that they don't want to ask someone outside [...] So we need... a way... to give*
15 *confidence to women to be able to speak to their GP or health visitor about their fear of*
16 *FGM without feeling criminalised."* (KIF17)
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20 Many participants highlighted the gap between communities and statutory agencies and the
21 need for engagement models that facilitated improved trust, confidence, and access (KIF15;
22 KIF15; KIF18; KIF17; KIF08).
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26 *Participation*

27
28 **The role of potentially-affected communities in participation interventions is described under**
29 **four** sub-themes: (i) communities' vital role, (ii) engagement and representativeness, (iii)
30 involvement in campaigns, and (iv) the value of a clear and inclusive national strategy.
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34 *Vital role:* Literature and interview sources highlighted that empowering affected communities
35 was the only way to end FGM[7, 12, 13, 23]. All participants emphasised the key role of
36 potentially-affected communities, indicating it was vital to ensure interventions were informed
37 by the experiences, needs and views of those affected by FGM.
38

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40 *'Anything around FGM needs to be championed and developed with people affected at*
41 *the centre and leading the work.'* (CG1)
42
43

44 Supporting and enabling community organisations to participate in policy-making was
45 identified as essential.
46

47 *'Finding ways and mechanisms to give [community organisations] that capacity, the*
48 *framework and leverage for them to be heard [is] very important because I don't*
49 *believe we can effectively abandon FGM in Europe [...] if those communities are not*
50 *the ones...acting for the abandonment of FGM. It's a very important role and only they*
51 *can actually do it.'* (KIF10)
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3 *Engagement and representativeness:* Despite consensus on its value, most participants said
4 insufficient efforts were made by policy-makers and practitioners to engage with communities
5 (KIF06; KIF01; KIF07; KIF17; KIF18). This was particularly evident in the UK, with existing
6 approaches described as *'piecemeal'* (KIF15) and *'tokenistic'* (KIF17; KIF18). Community
7 participants cited examples of being excluded or included at the last minute to *'tick a box'*
8 (KIF17) or when statutory professionals had a crisis (KIF18). In contrast, engagement in the
9 Netherlands was described as *'active'* (KIF05; KIF18).

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13 *'I don't think there's any such thing as a hard-to-reach group. I think there's*
14 *something called 'failed-to-reach groups by the statutory agencies' because there'll*
15 *always be individuals or an organisation who'll get you access to affected*
16 *communities.'* (KIM12)

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20 Participants noted a tendency of UK decision-makers to engage with the same handful of
21 individuals as *'leaders'* or *'spokespeople'* (KIF18). One highlighted the difference between
22 enabling individual community members to participate and working with community
23 organisations.

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26 *"[Community organisations] are bringing more than just their personal opinion, they*
27 *tend... to be engaging more widely with the community and so can be a channel to*
28 *have these voices heard."* (KIF18)

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32 Representativeness appeared to be a particular challenge for countries newer to FGM issues
33 (e.g. Portugal) as community organisations might not yet exist around this issue or have
34 confidence and advocacy experience (KIF18). Thus, whether effective or *'active'* participation
35 was achieved appeared to vary between - and sometimes within – countries, potentially
36 depending on whether decision-makers valued community organisations.

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40 *"It depends... whether the local authority [...] values community interventions and*
41 *whether they see the community as a problem and... statutory professionals as the*
42 *answer...or whether [the local authority] views the community as part and parcel of*
43 *[...] the solution."* (KIF18)

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47 UK participants noted that most FGM work occurred in silos, further challenging effective
48 participation. Interventions focused solely on FGM failed to account for *'gendered social*
49 *norms... and nature of women's lives'* (KIF15)[30]. Participants indicated that separating
50 FGM from issues like domestic violence was a major problem.

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53 *"They are seen as completely separate topics or discrete topics as opposed to how*
54 *do these principles cut across the way we navigate our communities and navigate our*
55 *spaces."* (KIF18)

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4 *Campaigns*: Several participants said that communities played an important role in
5 campaigning and awareness-raising. The Europe-wide End FGM Campaign led by Amnesty
6 International Ireland and the lobbying work of GAMS, a large French NGO founded in 1982
7 by women of African and Western origin, were highlighted (KIF02). Others spoke of the
8 important work of high profile survivor-campaigners, such as Layla Hussein in the UK
9 (KIF07). One participant talked about her own role as a community campaigner in '*raising*
10 *awareness through fashion...music and culture nights*' and '*campaigning, lobbying and*
11 *working with the government*' (KIF07).
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18 *Strategy*: Several participants noted that addressing FGM required strong strategic
19 frameworks. Most suggested this should be a resourced, standalone, multi-agency, national
20 action plan, developed in partnership with key stakeholders, including affected communities:
21

22 *"Authorities should... design a plan of action on FGM and...attach a budget to it and [it]*
23 *should not only be developed by officials in their offices but in collaboration with the*
24 *communities themselves and with all stakeholders."* (KIF06)
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28 At least eight European countries had developed national FGM action plans by 2013[1] and
29 Scotland did so in 2016[31]. There were very few examples across Europe of communities
30 having a role in strategy development or being supported to influence policy and practice.
31 The Finnish National Action Plan provided an example of community engagement, as it was
32 developed by a working group of government ministries and African women's
33 organisations[1]. Scotland's national action plan incorporated clear actions on community
34 participation, but participants noted limited engagement with communities in its development
35 (KIF17) and a general absence of community voices in the policy arena in Scotland (CG1;
36 CG2; KIF17). Participants in several European countries noted disconnects between policy
37 and reality.
38

39 *"One thing we're missing which is the reality for many European countries, is the*
40 *grassroots... There's a lot of awareness and there's a lot of policy but somehow we don't*
41 *understand what's happening at the grass roots."* (KIF07)
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49 ***Barriers to community participation***

50 The main barriers identified to effective work with communities were: (i) cultural, i.e. within
51 communities; (ii) structural, i.e. external to communities; and (iii) sustainability-related.
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54 *Cultural*: Leadership of FGM work is not easy and participants described the importance of
55 supporting community-members taking on such roles, e.g. through training, information, and
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3 access to services (KIF05; KIF13; KIF13). Negative consequences for community leaders or
4 activists have been documented[32], including verbal abuse, criticism, threats, and family
5 conflict (KIF05; KIF04; KIF17).
6

7 *“I’ve had people from my community who have sent me...hate messages, saying...
8 what you’re doing is wrong. And I’ve had family-members who have said that they
9 will no longer speak to me... and that I... bring shame on them. It’s not... easy for me
10 to take on this role. Trust me, there were times when I almost gave up” (KIF17)*
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14 Women may worry about bringing shame on their communities or experience shame or guilt
15 if they speak about FGM to service providers or other ‘outsiders’ (KIF17; KIF16)[33],
16 particularly as some communities are explicitly told not to speak about FGM (KIF17). Trust-
17 related barriers were thus common between communities and professionals (KIF07; KIF04),
18 particularly within child protection (KIF18) or health services, where usage of interpreters
19 could compound trust issues (KIF16; KIF17). Taking time to build trust was therefore deemed
20 important
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25 *‘It’s not a case of turning up with knowledge, but of starting off with the knowledge of
26 communities themselves, then building something together’ (KIF02)*
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29 Gender norms and power dynamics within potentially-affected communities were identified
30 as potential barriers, with several participants highlighting the importance of working with
31 men and women separately before bringing them together if appropriate (KIF04; KIF07).
32 While gender oppression was a structural barrier experienced by women globally, “its
33 manifestation differs according to culture, country and social grouping”[27], thus affecting
34 which avenues were open to women to challenge or engage with FGM and other aspects of
35 their lives[30, 34].
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41 *Structural:* Lack of understanding among professionals of the value and potential role of
42 communities was highlighted as a key barrier to their involvement in interventions. Key
43 decision-makers and service providers would need to change the ways in which they work to
44 ensure that communities were actively involved and heard. One participant provided an
45 example of statutory professionals in Bristol who developed alternative ways of engaging
46 with communities including attending community events, holding informal consultations, and
47 making meetings and meeting space more equitable and community friendly (KIF18). Lack of
48 compensation for travel and childcare expenses was cited as a barrier by several
49 participants, including a lack of understanding by some professionals of why such expenses
50 would even be required (KIF06; KIF17; KIF18).
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56 *‘It still feels like there is a need to explain the added value of communities to the*
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3 *powers that be.'* (KIF18)
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6 *Sustainability:* Participants in different contexts raised concerns about the sustainability of
7 FGM interventions, particularly those at community level that required long-term investment.
8 Some indicated that although community-led organisations were often approached for their
9 expertise, they were rarely funded for this advisory role (KIF15) and that significant
10 government funding was needed (KIF06; KIF15). Others highlighted the need for longer-term
11 investment in implementation and action beyond developing protocols, frame-works, and
12 action plans (KIF15; KIF03). Several noted that much of the work of community organisations
13 was not financially valued, with one participant stressing how important it was to recognise
14 the challenging nature of this work, which is '*under-valued and under-resourced*', and
15 questioning how long community members could continue to volunteer in such challenging
16 roles (KIF15).
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23 **Discussion**

24 *Principle findings*

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26 Clear consensus emerged that potentially-affected communities should have a role in all
27 intervention areas and that this was vital to addressing FGM in Europe[1, 15, 25]. Despite
28 this consensus and several examples of good practice (e.g. EU-funded REPLACE and
29 REPLACE 2 programmes, Dutch *Ketenaapak*, the Tackling FGM Initiative), community roles
30 remained inconsistent in FGM interventions and often non-existent in FGM policy
31 development.
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37 Practices ranged from good examples of support for community-led interventions and
38 partnership work with communities to less positive examples of tokenism and non-
39 participation. Most FGM interventions across Europe focused on awareness-raising, and
40 despite examples of good practice noted above, community participation appeared fairly
41 minimal[1, 15]. The extent of community participation was inconsistent between and within
42 countries. While community participation was accepted as vital, participants noted that
43 practices associated with community participation varied enormously. This corresponded
44 with the significant literature highlighting challenges inherent in increasing community
45 participation, e.g. what level of participation[35, 36], '*who participates, in what, and for whose*
46 *benefit*[37], and to what extent government organisations that engage with communities
47 could change to develop truly participatory processes and spaces[38].
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55 The role of communities appeared most developed within prevention interventions, with good
56 practice examples of both community-led initiatives and partnership. Protection-focused
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3 approaches were more challenging in terms of participation, as the clear child-protection
4 focus could stigmatise families[1, 7]. Community participation within safeguarding varied,
5 with examples of both effective and emerging roles. Individuals and organisations had roles
6 in building trust and bridging gaps between communities and authorities, though
7 responsibility for managing risk should remain firmly with statutory bodies[25]. While several
8 community-led organisations delivered a range of services, few examples were found of
9 communities participating in designing, delivering or evaluating statutory services. Good
10 practice examples were identified of community organisations or activists playing a key role
11 in facilitating services access and enabling dialogue within communities to occur[25].
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16 17 *Implications for policy and practice*

18 Engaging potentially-affected communities in coordinated multi-agency responses appears
19 critical to the success of FGM policies and interventions in Europe. Decision-makers and
20 service providers should invest in community engagement by (i) ensuring that community
21 organisations can participate actively in future interventions and (ii) addressing cultural,
22 structural, and sustainability-related barriers to participation.
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27 Supporting and strengthening community organisations can improve engagement. Bottom-up
28 approaches that enable dialogue within communities appear most successful. Community
29 development support could enable potentially-affected communities to identify their own
30 FGM-related concerns and aspirations and work collectively to identify solutions and take
31 action. This requires long-term investment in community development support and
32 community organisations themselves, to support community-led interventions and
33 meaningful engagement between communities and policy-makers. Any engagement with
34 communities must begin with identifying those communities potentially affected,
35 acknowledging that communities are not homogenous, and engaging with a wide range of
36 groups and community representatives across nationalities and ethnicities. As most women
37 and girls affected by FGM also identify as people of colour, perspectives and lived
38 experiences must be included in development of meaningful policies and services.
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46 Research on FGM interventions across Europe is limited, when compared to levels of
47 activism. Research has focused on clinical care, provision of health services, and attitudes
48 towards FGM. Minimal investigation has been conducted on the role of diaspora
49 communities and their contributions to challenging and responding to FGM. Empowerment,
50 engagement, and participation are frequently mentioned, but rarely critically examined, with
51 little discussion about how to move beyond rhetoric towards putting these concepts into
52 practice. Further research with communities, including participatory methods, appears
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warranted. Any such research should include the voices of affected women and girls, as those best able to describe their lived experiences and needs and to contribute to the additionally sensitive topics of prosecution and redress.

Limitations

This study had three significant limitations. First, this study was exploratory and participant numbers were limited due to time and resource constraints. Second, numbers of participants from potentially-affected communities were limited and further community engagement is needed to expand on issues raised. Finally, focus on European interventions ignored the successfully designed and implemented African interventions, e.g. TOSTAN (www.tostan.org) that offer international benchmarks for changing attitudes and reducing FGM[21].

Conclusion

Exploring the role of communities within interventions to address FGM in Europe allowed critical examination of how crucial community voices remain marginalised and could be better heard and supported. “*Without an effective commitment to the participation and empowerment of potentially-affected communities, policy-makers and practitioners will not identify the actual risks experienced by diaspora girls and women in Europe or develop effective interventions, and risk further marginalising those community voices that are the most effective advocates for change*”[6]. Results demonstrate that it is possible to work alongside potentially-affected communities, benefitting from community perspectives and expertise, to develop meaningful partnerships and support community-led interventions.

Declarations

Conflict of interest

None declared.

Author contributions

EC contributed to study design, data collection and analysis and drafted the manuscript. NM contributed to study design, data analysis, and manuscript writing. HB contributed to study design, data collection and analysis, and critically reviewed the manuscript. NH contributed to study design and data interpretation and critically revised the manuscript. All authors approved the version for submission.

Acknowledgements

Special thanks to all key informants, particularly women from potentially-affected

communities, for their invaluable insights.

Funding

This work was supported by the Scottish Government Equality Fund and Rosa FGM Small Grants Programme for funding research.

Data sharing

Anonymised dataset and coding are available on request in accordance with LSHTM institutional data management policy.

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For peer review only

Tables

Table 1. Key definitions

Female genital mutilation	All procedures that involve partial or total removal of the female external genitalia, or other injury to the female genital organs for non-medical reasons (WHO, 2016)
Community	A community of identity has a common bond based on ' <i>geography, identity or interest</i> ' [10]
Community development	Community development enables people to work collectively to bring about positive social change. This long-term process starts from people's own experience and enables communities to work together to: <ul style="list-style-type: none"> • identify their own needs and actions; • take collective action using their strengths and resources; • develop their confidence, skills and knowledge; • challenge unequal power relationships; • promote social justice, equality and inclusion; to improve the quality of their own lives, the communities in which they live and societies of which they are a part [10]
Participation	Policy-making and practice development around violence against women is shaped by the experiences, needs and views of those affected by FGM [6]
Potentially-affected community	A diaspora community from one of 29 countries identified by UNICEF, in which FGM practices are concentrated, i.e. Somalia 98%, Guinea 96%, Djibouti 93%, Egypt 91%, Eritrea 89%, Mali 89%, Sierra Leone 88%, Sudan 88%, Gambia 76%, Burkina Faso 76%, Ethiopia 74%, Mauritania 69%, Liberia 66%, Guinea-Bissau 50%, Chad 44%, Cote d'Ivoire 38%, Kenya 27%, Nigeria 27%, Senegal 26%, CAR 24%, Yemen 23%, Tanzania 15%, Benin 13%, Iraq 8%, Ghana 4%, Togo 4%, Niger 2%, Cameroon 1%, Uganda 1% [5, 39]
Prevention	Interventions intended to create and/or sustain behavioural and attitudinal change within affected communities [6]
Protection	Interventions intended to protect the individual rights of women and girls who are at risk of or have experienced FGM [6]
Service provision	Service responses to survivors of FGM [6]

Table 2. Participant characteristics

ID	Role/Title	Location	Interview type
KIF01	University professor	Spain (Skype)	KII
KIF02	NGO worker	France	KII
KIF03	NGO worker	Netherlands	KII
KIF04	Teacher	England	KII
KIF05	Government minister	Netherlands	KII
KIF06	University professor	Belgium	KII
KIF07	Community activist	Ireland (Skype)	KII
KIF08	Medical professional	England	KII
KIF09	University professor	France	KII
KIF10	INGO worker	EU	KII
KIF11	Solicitor	Scotland	KII
KIM12	Police officer	England	KII
KIF13	Police officer	England	KII
KIF14	Legal professional	France	KII (unrecorded)
KIF15	NGO worker	England	KII
KIF16	Medical professional	Scotland	KII
KIF17	Community activist	Scotland	KII
KIF18	Community activist	Scotland	KII
EG1	9 policy/practice participants	Scotland	Group interview
EG2	9 policy/practice/community participants	Scotland	Group interview
EG3	10 policy/practice/community participants	Scotland	Group interview
CG1	4 community activists	Scotland	Group interview
CG2	4 community activists	Scotland	Group interview

BMJ Open

Missing from the debate? A qualitative study exploring the role of communities within interventions to address female genital mutilation in Europe

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2017-021430.R2
Article Type:	Research
Date Submitted by the Author:	26-Apr-2018
Complete List of Authors:	Connelly, Elaine; Scottish Refugee Council Murray, Nina; Scottish Refugee Council Baillot, Helen; Scottish Refugee Council Howard, Natasha; London School of Hygiene & Trop Med, Global Health and Development
Primary Subject Heading:	Public health
Secondary Subject Heading:	Health policy
Keywords:	

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3 **Missing from the debate? A qualitative study exploring the role of communities within**
4 **interventions to address female genital mutilation in Europe**
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26 **Key words**

27 FGM, female genital cutting, community development, Europe
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Abstract

Introduction

Public attention on female genital mutilation in diaspora communities is increasing in Europe, as health and social welfare implications become better understood. This study explored the role of potentially-affected communities within interventions to address female genital mutilation in Europe, examining current practices, promising interventions, and remaining gaps.

Methods

A qualitative study design incorporated 18 individual key informant interviews and five semi-structured group interviews with policy-makers, service providers, and community representatives. Data were analysed thematically, guided by the Scottish Government '4Ps' framework for addressing violence against women and girls, i.e. prevention, protection, provision of services, and participation.

Results

Participants emphasised both the importance of community participation and the lack of consistent engagement by policy-makers and practitioners. All indicated that communities had a key role, though most interventions focussed on awareness-raising rather than community empowerment, behaviour change, or influence on the design, delivery, and/or evaluation of interventions.

Conclusions

Despite clear consensus around the need to engage, support, and empower potentially-affected communities and several examples of meaningful community participation in addressing female genital mutilation (e.g. REPLACE, REPLACE 2, *Ketenaapak*, Tackling FGM Initiative), the role of communities remains inconsistent and further engagement efforts are necessary.

Strengths and limitations

- This study was exploratory and participant numbers were limited, including members of potentially-affected communities, due to time and resource constraints.
- Study focus was on European interventions, thus excluding many innovative and successful African interventions.
- Nevertheless, this study is a rare effort to examine the under-researched role of diaspora communities in initiatives to address female genital mutilation in Europe, drawing from in-depth and semi-structured key informant interviews.

Introduction

Female genital mutilation (FGM), a practice, defined in Table 1, that expresses '*deeply entrenched gender inequalities, grounded in a mix of cultural, religious and social facts inherent within patriarchal families and communities,*' is recognised internationally as a violation of the fundamental rights of women and girls and a serious form of gender-based violence[1]. Health implications of FGM are wide-ranging and well-established. Immediate health consequences include shock, haemorrhage, infection, and psychological trauma, while long-term risks include chronic pain, infections, cheloids, primary infertility, urogenital complications, birth complications, and danger to newborns[2, 3]. Though sometimes referred to as 'cutting' or 'female circumcision', this article uses 'FGM' to acknowledge the harm to women and communities.

Data indicate the existence of large communities potentially-affected by FGM in many European countries[1, 4]. For example, 23,979 people born in one of 29 'FGM-practising countries'[5], were living in Scotland in 2011[6]. However, attempts to estimate numbers of women and girls who have undergone or are at risk of FGM in diaspora communities in Europe have proven difficult due to data limitations and lack of agreement on prevalence estimation methods[4]. Additionally, the extent to which migration experiences may change attitudes and practices remains under-researched[7]. This article uses the term 'potentially-affected communities' to avoid presumptions attached to 'FGM practising communities' that may be inaccurate in a migratory context[8].

The concept of community is not straightforward, with a range of contradictory and related meanings used on all sides of the political spectrum[9]. Often defined by geography, interest, or identity, communities are not homogenous or static but rather diverse, dynamic, and multifaceted entities[10]. This article primarily describes communities of identity, where the common bond is often nationality, ethnicity, and the experience of exile, although some may also be issue-based or geographical.

FGM is described as a '*tradition in transition*'[11], with some experts asserting that empowering affected communities will lead to its elimination[7, 12, 13]. Public, media, and political attention on FGM in diaspora communities within Europe has increased, but often focuses on criminal justice and child protection[14]. While many European countries have enacted legislation and policy initiatives, the role of communities in interventions addressing FGM remains limited[1, 14]. Little research has been conducted on the role of communities in FGM interventions and very few have been rigorously evaluated[15]. Thus, community

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3 voices are generally missing from FGM policy debates and partnerships, despite growing
4 consensus that communities are key in addressing FGM[16]. Working with potentially-
5 affected communities may provide a key opportunity, as the process of migration and exile
6 allows communities to reflect, question, and debate traditional beliefs[17, 18].
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10 This study aimed to explore the role of communities within interventions to address FGM in
11 Europe, describing perspectives of practitioners, activists, and community representatives on
12 current practices, promising interventions, and gaps that should be addressed. Findings are
13 presented using the Scottish Government's 4Ps framework (i.e. prevention, protection,
14 provision of services, participation) described in its strategic approach to tackling violence
15 against women[19]. This approach reflects and builds upon European level work, e.g. the
16 European Institute for Gender Equality identifies five focus areas (i.e. prevalence, prevention,
17 protection, prosecution, provision of services) as does the Due Diligence Standard of the
18 Istanbul Convention (i.e. prevent, protect, prosecute and punish, provide services and
19 redress) that was signed by 47 countries with FGM interventions[1, 20]. Thus, themes have
20 relevance for policy-makers, researchers, community development practitioners, and
21 professionals working with potentially-affected communities.
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29 **Methods**

30 *Study design*

31 A qualitative study design was selected, drawing on data from a scoping literature review[21]
32 and interviews (i.e. individual and group) with Europe-based academics, legal professionals,
33 statutory and voluntary service providers, community activists, and representatives from
34 potentially-affected communities. The research question was "*What is the role of potentially-*
35 *affected diaspora communities in interventions that respond to and challenge FGM in*
36 *Europe?*" Table 1 provides definitions used.
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43 *Participant sampling and recruitment*

44 Individual interview participants were recruited purposively to include academics, policy-
45 makers, police officers, NGO staff, and community activists in EEA member countries with
46 recognised FGM responses. Initially, interview participants were identified through the
47 literature review[21] (i.e. conference presenters and lead authors, and other authors
48 appearing in more than one article, were invited by email). Additionally, heads of relevant
49 government departments, NGO programme staff, and community activists known for their
50 FGM expertise related to one or more of the '4P' focus areas were contacted by phone or
51 email. Lastly, further recruits were identified through snowball sampling from participants. Of
52 27 invitees, 18 participated. The nine non-respondents gave no reason for not responding to
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3 email invitations or telephone reminder, but all were busy professionals with varied roles and
4 worked at different levels across the EU and there were no identifiable differences between
5 respondents and non-respondents.
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9 Group interview participants were recruited purposively to include senior and mid-level
10 policy-makers, statutory and voluntary service providers, and community representatives
11 selected for their FGM expertise and activism. Potential participants were selected from
12 managers of relevant government departments, NGOs, community organisations, and
13 activists who had worked with Scottish Refugee Council on women's rights projects. To
14 reduce barriers to participation for some community representatives, travel expenses and
15 childcare were provided. Of 59 invitees, 36 participated. Group interviews were all conducted
16 on the same day, and thus more people were intentionally invited than were expected to
17 attend, with non-participation reported as due to lack of availability. However, all invited
18 agencies and groups were represented.
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24 25 *Data collection*

26 *In-depth key-informant interviews* were conducted by EC and HB in English and French
27 using a topic guide based on the 4P framework. Interviews lasted approximately 60 minutes,
28 were audio recorded and/or scribed depending on permission, and conducted privately in
29 locations of participants' choosing. Additional participants were recruited until researchers
30 were confident that data saturation had been achieved[22].
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35 *Semi-structured group interviews* were facilitated by EC and NM in English using an
36 interview guide based on the 4P framework. Discussions lasted approximately 1.5 hours,
37 included 4-9 participants, were audio-recorded and/or scribed, and facilitated in a central
38 Glasgow venue.
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43 All participants received a study information sheet, had their questions answered, and
44 provided written informed consent prior to interview. Approximately a third of participants
45 knew researchers professionally prior to interview, due to their work with refugees, violence
46 against women, or community development. Additionally, EC, HB, and NM summarised the
47 research purpose, reasons, and their interest in the topic.
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51 *Analysis and reporting*

52 Data were analysed thematically, as described in Braun and Clarke[23]. The Scottish
53 Government's strategic approach to preventing and eradicating violence against women and
54 girls '4Ps' framework (i.e. prevention, protection, provision, participation) was used for initial
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3 deductive coding. Additional themes and sub-themes were captured using inductive coding.
4 EC and NM coded data using *Dedoose* software, with checks by HB. Discrepancies were
5 resolved through discussion and agreement among all authors. Reporting adhered to
6 COREQ criteria for qualitative research[24].
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10 *Patient and public involvement*

11 As 'patient involvement' was not applicable to this study, community advocates and women
12 from potentially-affected communities acted as civil society and public representatives.
13 Development of research question and outcome measures were informed by women's
14 priorities, experience, and preferences through consultation with women's groups and review
15 of unpublished literature. Women and advocates from potentially-affected communities were
16 involved in study recruitment and conduct through the use of snowball sampling of
17 participants and review of initial findings. Results were disseminated to study participants
18 through sharing of the technical report, invitation to the report launch event, and open access
19 publication of related articles.
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26 *Ethics*

27 The Research Ethics Committee of the London School of Hygiene & Tropical Medicine
28 granted ethics approval (reference 7977).
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32 **Findings**

33 Table 2 shows 18 individual interviews were conducted with participants working EU-wide
34 and/or in seven countries with active interventions addressing FGM (i.e. Belgium, England,
35 France, Ireland, Netherlands, Scotland, Spain). Five group interviews were conducted with a
36 total of 36 policy-makers, service providers, and community representatives. Community
37 participants, from Sudan, Somalia, Gambia, and Uganda, were activists or representatives of
38 voluntary or community-led organisations working to address FGM.
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44 The role of communities is reported under the four 4Ps framework themes and one emergent
45 theme (i.e. barriers to involvement). Each thematic section includes analysis of the extent to
46 which potentially-affected communities were involved in addressing FGM in Europe
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50 *Prevention*

51 The role of potentially-affected communities in prevention is described under three emergent
52 sub-themes of: (i) women's leadership; (ii) roles of men, youth, and religious leaders; and (iii)
53 effective prevention interventions.
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3 *Women's leadership:* Participants identified women from potentially-affected communities,
4 including survivors, as playing key roles in addressing FGM. Provided they had the trust and
5 respect of their communities, these '*knowledgeable cultural guides*' [25] were considered
6 central to changing community behaviours. A participant explained that while '*it doesn't need*
7 *to be a survivor...you do need someone from that community*' (KIF07). Norman and
8 colleagues noted the effectiveness of messages from within communities:
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11 *'Women's arguments against FGM, spoken fluently and in their own words and*
12 *crucially, coming from within the community, provide an important resource for those*
13 *working to end FGM*[16]
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18 A UK participant highlighted the significance of a women-led '*African diaspora organisation*'
19 addressing FGM:

20 *"People recognize that we seem to have some kind of understanding of the issues...*
21 *We...brought a woman from Somalia to deliver a session on social services and*
22 *safeguarding children. It was a different dynamic... because this is somebody from the*
23 *community talking about these issues."* (KIF15)
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28 *Roles of men, youth, and religious leaders:* While women from affected communities have
29 been vital in prevention interventions, participants identified the important male role that was
30 often missing.

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32 *'Something that's really missing is when we talk about the community, we always*
33 *target women, but what about the men, are they not part of the decision-making?*
34 *FGM is not only the woman's decision.'* (KIF07)
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39 Male perspectives provided deeper reflection about cultural complexities surrounding FGM
40 and the most common arguments for its continuation[26]. One participant noted that men
41 were increasingly involved and no longer viewed FGM as strictly '*women's business*' (KIF02).
42 Another participant noted that men in migratory contexts were far more likely to be involved
43 than in countries of origin (KIF09). In the Netherlands, involving men was common:

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45 *'I never heard it was difficult to involve men and the men I've spoken with are very*
46 *passionate.'* (KIF05).
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51 Participants identified young people as critical '*advocates of change*' (KIF15) and '*parents of*
52 *the next generation*' (KIF04), able to speak freely about FGM and more likely to become
53 involved in community activism. One participant noted that young people were most at risk of
54 FGM and so educating and working with young people was vital if girls were expected '*to*
55 *come forward and express their fear of having FGM*' (KIF17). Examples of innovative work
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3 with British young people included Daughters of Eve, Integrate Bristol, and FORWARD. In
4 Ireland and the UK, young people were involved in projects including *'using films and*
5 *resources to support [...] statutory professionals in schools'* (KIF07), and developing poetry,
6 radio documentaries, films, and music videos to *'encourage that conversation to happen in*
7 *as many different settings as you can'* (KIF04).
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11 Religious leaders influenced many communities and therefore could play a *'pivotal and*
12 *respected role*[27]. As one participant stated, *'in our community when we are worried about*
13 *anything we contact our religious leaders'*, suggesting involvement of religious leaders could
14 be key (KIF17). Most religious leaders were men, potentially easing work with other men
15 (KIF17). However, another source noted the need *'to critically examine the added benefit'* as
16 preventative work had challenged the religious justifications of FGM without necessarily
17 involving religious leaders[27].
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23 *Perceived effective interventions:* The World Health Organisation (WHO) recommended a
24 shift from awareness-raising to behaviour change approaches in 2009[1]. However, despite
25 some exceptions, prevention interventions focused on awareness-raising rather than
26 empowerment and targeted behaviour change[1, 15]. Awareness-raising approaches often
27 had broad target audiences and aims rather than focusing on communities most at risk.
28 Thus, *'key targets ...may not be fully reached or engaged'*[1]. Equally, approaches that
29 focused on individual change, without acknowledging community belief systems, have
30 resulted in slow progress addressing FGM across Europe[15]. When community
31 organisations and statutory professionals worked together on prevention work, using joint
32 messages on ending FGM, FGM rejection reportedly increased[27, 28].
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40 Participants identified EU-funded REPLACE and REPLACE2 programmes as *'effective*
41 *prevention interventions'*, focused on Belgium, England, Italy, the Netherlands, Portugal, and
42 Spain. REPLACE developed a toolkit for conducting participatory action research (PAR) with
43 communities and a behaviour change cycle framework for enabling community members to
44 take action to end FGM[15]. Enabling community members themselves to gather data from
45 within their communities ensured that *'research is conducted 'with' rather than 'on' the*
46 *community*[15].
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50 *"[REPLACE is] innovative because it focuses on behaviour change; it works directly*
51 *with the communities, which is quite exceptional in Europe [...It is] framed in a theory of*
52 *behaviour change, which really has a thorough methodology... and also an evaluation."*
53 (KIF06)
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3 Participants identified PAR approaches generally as 'good practice', able to provide in-depth
4 understanding of the interventions needed with particular communities. Participants identified
5 a PAR initiative called Participatory Ethnographic Evaluation and Research, developed by
6 Options and Swansea University, as "*an eye opener for a lot of the community members*"
7 (KIF15) who recognised that FGM must be addressed in their community and went on to play
8 key roles in other FGM interventions.
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13 Participants described *Ketenaapak* ('Dutch Chain Approach') in the Netherlands as
14 'particularly effective'. This model was described as a '*meaningful initiative to involve*
15 *communities in FGM prevention work and a landmark in the prevention of FGM in the*
16 *Netherlands*[1]. In this multi-disciplinary approach, over 100 key community figures
17 contributed to child protection and prevention through organising home visits and meetings
18 within their communities to raise FGM awareness (KIF05). Several participants identified the
19 *Federation of Somali Associations in the Netherlands (FSAN)* as a grassroots organisation
20 playing an important role in identifying key figures within communities, coordinating activities,
21 and providing training (KIF02; KIF03),
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28 The Tackling FGM Initiative (TFGMI), established in the UK in 2010, was a six-year
29 collaboration between five funding bodies to strengthen community-based preventative
30 work[28]. It provided many examples of good practice focused on community-led prevention
31 and participation in activities across the UK, highlighting the crucial role of community
32 'champions' supported by community organisations[27]. For example, a Manor Gardens
33 training programme enabled London women and men to become paid Community
34 Facilitators and work with healthcare professionals to organise FGM sessions (KIF18).
35 Another example, Africa Advocacy Foundation, relied on social networks to create '*sister*
36 *circles*' (safe spaces for women) to enable community conversations around FGM in
37 Southeast London[27]. Safe, women-only spaces were considered important '*for women to*
38 *discover for themselves the nature of their reality through discussions with other women*'[29],
39 as a first step in rejecting FGM[27]. As one participant noted, '*one of the mistakes we make*
40 *is that we assume everyone knows that FGM is harmful whereas many women from*
41 *communities or women who have experienced FGM don't see that*' (KIF17).
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50 *Protection*

51 The role of potentially-affected communities in protection is described under two sub-themes
52 (i) prevention-protection linkages and (ii) effective protection.
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3 *Prevention-protection linkages:* Despite consensus that legislation and criminal justice
4 approaches helped provide an enabling framework for prevention work, participants noted
5 that such approaches could not succeed without a parallel focus on prevention.
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7 *“Given the deep-rooted cultural nature of harmful traditional practices, we can mount*
8 *as many arrests as we possibly can [...], but unless...an affected community changes*
9 *their thinking, then we’re never going to truly...prevent or...eradicate these practices.”*
10

11 (KIM12)
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14 Prevention and protection were described by one participant as *‘two sides of the same coin,*
15 *neither can succeed without the other’* (KIF14). However, there are recognised tensions
16 between these approaches[1, 30]. Preventive approaches are generally more collaborative[1]
17 and community-focused[30]. Protection approaches, whilst perhaps necessarily promoting an
18 unequivocal message around child protection, may lead to families being viewed as potential
19 perpetrators[1]. Several participants highlighted that culturally aggressive top-down
20 approaches imposed on communities, without the building of trust between families and
21 professionals, could have unwanted consequences, e.g. girls being taken abroad for FGM
22 (KIF01)[7] or already marginalised families, pushed further from mainstream society,
23 *‘cling[ing] to their own cultures and traditions more tightly*[30].
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31 Participants in France and the Netherlands reported some success in achieving attitudinal
32 change and reducing FGM through a combination of prevention and protection interventions.
33 In France, a number of high profile prosecutions and legislative measures had been
34 accompanied by investment in training and support for professionals, as well as education
35 and awareness-raising in schools and universities, though the role of communities was not
36 necessarily clear within this (KIF02). In the Netherlands (i.e. *Katenapaak*), participants
37 reported most success developing a crucial role for communities within combined prevention
38 and protection responses (KIF05). UK approaches were criticised for failing to effectively link
39 protection and prevention agendas and involve communities: *“...efforts to reduce FGM have*
40 *focused on punitive legislation without at the same time empowering women in communities*
41 *to engage in debate, change attitudes and create alternative ways of affirming their cultural*
42 *identity”*[14]. However, describing a successful Police-led community conference, a UK
43 participant suggested that this was shifting, with many organisations *‘motivated by the need*
44 *for change’* and prepared to support the police in developing *‘community-driven’* solutions
45 (KIM12).
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54 In discussing prosecutions, respondents highlighted the need for a person-centred *‘violence*
55 *against women and girls’* approach that struck the correct balance between the needs of
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3 affected women and girls and the need to eradicate the practice of FGM (KIM12). One of the
4 key barriers highlighted by respondents across different contexts was the likelihood that a
5 survivor would need to testify against her relatives, and the difficult question of how to
6 balance this against her best interests (KIF14, KIF13, KIM12, KIF06). Some suggested that
7 the lack of trust both between professionals, and between professionals and potentially-
8 affected communities, could hinder the investigations that could lead to prosecutions
9 (KIM12). A lack of understanding and knowledge about FGM and potentially-affected
10 communities among law enforcement officers was noted as another potential barrier to
11 prosecutions (KIF02). Some respondents identified an important role for NGOs, some of
12 which were established from within potentially-affected communities, in providing training to
13 police and prosecutors, stating that their “*knowledge, advice, guidance and support has been*
14 *absolutely instrumental*” (KIM12).
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22 *Effective protection:* Participants highlighted community involvement in protection
23 interventions in the Netherlands, UK, and Spain. UK participants noted statutory agencies
24 involving community organisations at an earlier stage when girls were identified as at risk of
25 FGM (KIF17, KIF18). For example, FORWARD in London and NEw STep for African
26 Community (NESTAC) in Manchester worked alongside authorities to deliver family
27 education sessions, overcoming language and cultural barriers to strengthen engagement
28 (KIF18). In Bristol, social services increased the capacity of community organisations to take
29 on ‘safeguarding’ roles, working together to ensure common understandings of risk (KIF18).
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35 However, some participants expressed reservations about communities’ role in protection
36 interventions, suggesting that statutory agencies passing on risk management responsibility
37 to community organisations was risky (EG1; KIF18). Another noted that community
38 organisations with experience of case management, e.g. around violence against women or
39 asylum-seekers, could better manage the complexities of taking on a protection role[27]. A
40 participant described the value of joint-working, in building community confidence to report
41 concerns.
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46 *“If there is a cutter in the community, the chances are higher that the community*
47 *members would be aware of it than a professional...we need to work with*
48 *communities to train them and empower them...so they can report for themselves.”*
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50 (KIF17)
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53 Other examples included developing tools to support protection of individual women and
54 girls. The Dutch Government produced a passport-sized declaration, signed by a range of
55 community and non-community organisations, stating that FGM is forbidden and punishable
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3 by a prison sentence and loss of rights to residency, which families can carry when travelling
4 overseas (KIF05). A Spanish region produced a similar official letter for families travelling
5 abroad (KIF01). Participants highlighted the need for such tools to be developed in
6 partnership with communities, as in the Netherlands. UK participants noted that when a
7 similar tool was developed by the UK Government, communities did not feel ownership of it,
8 lessening its impact (KIF15).
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12 13 *Provision*

14 The role of potentially-affected communities in services provision is described under two sub-
15 themes: (i) provision roles and (ii) facilitating access.
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19 *Provision roles:* Participants identified community organisations across Europe providing
20 services from advocacy to psychological support, e.g. Daughters of Eve, FORWARD, FSAN,
21 and GAMS - the *Groupe pour l'Abolition des Mutilations Sexuelles* (KIF03; KIF06, KIF15;
22 KIF17). Fewer examples existed of community organisations influencing the planning, design
23 or delivery of services, although participants concurred on the need for this (KIF17; KIF15;
24 KIF18).
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28 *"If communities are involved they can tell what kind of services they require, rather*
29 *than...you know coming from top down, where they make assumptions."* (KIF17)
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32 *Facilitating access:* Although community organisations seldom delivered clinical services,
33 they had an important role in facilitating women's engagement *"to understand why that*
34 *service exists and... taking the time to explain it ...which is something that many health*
35 *providers don't have the time to do"* (KIF17). UK participants described community
36 involvement in developing and delivering specialist services (KIF15; KIF18). For example, an
37 FGM clinic in Bristol was developed in response to lobbying from women who were involved
38 in its design and sat on its steering group (KIF18). A London project, developed to support
39 women failing to attend specialist appointments at an FGM clinic, involved community
40 members calling/meeting clients to explain appointments, which improved services uptake
41 (KIF18).
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49 In response to such barriers as a reluctance to disclose FGM to health professionals (KIF05),
50 a fear of being criminalised (KIF17), or a lack of trust (KIF18), compounded by health
51 providers' own discomfort and reluctance to initiate discussions around FGM[31], community
52 organisations and members were regarded as having a key role in facilitating access to
53 services. Participants identified an example of a service employing outreach workers from
54 the community who take on a '*mediating role*' (KIF18). In another example, the Dutch
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3 Government funded a community organisation to implement an awareness raising campaign
4 to get information to women about services available to them (KIF05). Another participant
5 described a more informal role.
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7 *"I often get people phoning me asking for advice and support... A lot of women would*
8 *say that they don't want to ask someone outside [...] So we need... a way... to give*
9 *confidence to women to be able to speak to their GP or health visitor about their fear of*
10 *FGM without feeling criminalised."* (KIF17)
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14 Many participants highlighted the gap between communities and statutory agencies and the
15 need for engagement models that facilitated improved trust, confidence, and access (KIF15;
16 KIF15; KIF18; KIF17; KIF08).
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20 *Participation*

21 The role of potentially-affected communities in participation interventions is described under
22 four sub-themes: (i) communities' vital role, (ii) engagement and representativeness, (iii)
23 involvement in campaigns, and (iv) the value of a clear and inclusive national strategy.
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28 *Vital role:* Literature and interview sources highlighted that empowering affected communities
29 was the only way to end FGM[7, 12, 13, 25]. All participants emphasised the key role of
30 potentially-affected communities, indicating it was vital to ensure interventions were informed
31 by the experiences, needs and views of those affected by FGM.
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34 *'Anything around FGM needs to be championed and developed with people affected at*
35 *the centre and leading the work.'* (CG1)
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38 Supporting and enabling community organisations to participate in policy-making was
39 identified as essential.
40

41 *'Finding ways and mechanisms to give [community organisations] that capacity, the*
42 *framework and leverage for them to be heard [is] very important because I don't*
43 *believe we can effectively abandon FGM in Europe [...] if those communities are not*
44 *the ones...acting for the abandonment of FGM. It's a very important role and only they*
45 *can actually do it.'* (KIF10)
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50 *Engagement and representativeness:* Despite consensus on its value, most participants said
51 insufficient efforts were made by policy-makers and practitioners to engage with communities
52 (KIF06; KIF01; KIF07; KIF17; KIF18). This was particularly evident in the UK, with existing
53 approaches described as *'piecemeal'* (KIF15) and *'tokenistic'* (KIF17; KIF18). Community
54 participants cited examples of being excluded or included at the last minute to *'tick a box'*
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3 (KIF17) or when statutory professionals had a crisis (KIF18). In contrast, engagement in the
4 Netherlands was described as 'active' (KIF05; KIF18).

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6 *'I don't think there's any such thing as a hard-to-reach group. I think there's*
7 *something called 'failed-to-reach groups by the statutory agencies' because there'll*
8 *always be individuals or an organisation who'll get you access to affected*
9 *communities.'* (KIM12)
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13 Participants noted a tendency of UK decision-makers to engage with the same handful of
14 individuals as 'leaders' or 'spokespeople' (KIF18). One highlighted the difference between
15 enabling individual community members to participate and working with community
16 organisations.
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19 *"[Community organisations] are bringing more than just their personal opinion, they*
20 *tend... to be engaging more widely with the community and so can be a channel to*
21 *have these voices heard."* (KIF18)
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25 Representativeness appeared to be a particular challenge for countries newer to FGM issues
26 (e.g. Portugal) as community organisations might not yet exist around this issue or have
27 confidence and advocacy experience (KIF18). Thus, whether effective or 'active' participation
28 was achieved appeared to vary between - and sometimes within – countries, potentially
29 depending on whether decision-makers valued community organisations.
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31
32 *"It depends... whether the local authority [...] values community interventions and*
33 *whether they see the community as a problem and... statutory professionals as the*
34 *answer...or whether [the local authority] views the community as part and parcel of*
35 *[...] the solution."* (KIF18)
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40 UK participants noted that most FGM work occurred in silos, further challenging effective
41 participation. Interventions focused solely on FGM failed to account for '*gendered social*
42 *norms... and nature of women's lives'* (KIF15)[32]. Participants indicated that separating
43 FGM from issues like domestic violence was a major problem.
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46 *"They are seen as completely separate topics or discrete topics as opposed to how*
47 *do these principles cut across the way we navigate our communities and navigate our*
48 *spaces."* (KIF18)
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52 *Campaigns:* Several participants said that communities played an important role in
53 campaigning and awareness-raising. The Europe-wide End FGM Campaign led by Amnesty
54 International Ireland and the lobbying work of GAMS, a large French NGO founded in 1982
55 by women of African and Western origin, were highlighted (KIF02). Others spoke of the
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3 important work of high profile survivor-campaigners, such as Layla Hussein in the UK
4 (KIF07). One participant talked about her own role as a community campaigner in '*raising*
5 *awareness through fashion...music and culture nights*' and '*campaigning, lobbying and*
6 *working with the government*' (KIF07).
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10 *Strategy*: Several participants noted that addressing FGM required strong strategic
11 frameworks. Most suggested this should be a resourced, standalone, multi-agency, national
12 action plan, developed in partnership with key stakeholders, including affected communities:

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14 *"Authorities should... design a plan of action on FGM and...attach a budget to it and [it]*
15 *should not only be developed by officials in their offices but in collaboration with the*
16 *communities themselves and with all stakeholders."* (KIF06)
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20 At least eight European countries had developed national FGM action plans by 2013[1] and
21 Scotland did so in 2016[33]. There were very few examples across Europe of communities
22 having a role in strategy development or being supported to influence policy and practice.
23 The Finnish National Action Plan provided an example of community engagement, as it was
24 developed by a working group of government ministries and African women's
25 organisations[1]. Scotland's national action plan incorporated clear actions on community
26 participation, but participants noted limited engagement with communities in its development
27 (KIF17) and a general absence of community voices in the policy arena in Scotland (CG1;
28 CG2; KIF17). Participants in several European countries noted disconnects between policy
29 and reality.
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35 *"One thing we're missing which is the reality for many European countries, is the*
36 *grassroots... There's a lot of awareness and there's a lot of policy but somehow we*
37 *don't understand what's happening at the grass roots."* (KIF07)
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41 ***Barriers to community participation***

42 The main barriers identified to effective work with communities were: (i) cultural, i.e. within
43 communities; (ii) structural, i.e. external to communities; and (iii) sustainability-related.
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47 *Cultural*: Leadership of FGM work is not easy and participants described the importance of
48 supporting community-members taking on such roles, e.g. through training, information, and
49 access to services (KIF05; KIF13; KIF13). Negative consequences for community leaders or
50 activists have been documented[34], including verbal abuse, criticism, threats, and family
51 conflict (KIF05; KIF04; KIF17).
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54 *"I've had people from my community who have sent me...hate messages, saying...*
55 *what you're doing is wrong. And I've had family-members who have said that they*
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3 *will no longer speak to me... and that I... bring shame on them. It's not... easy for me*
4 *to take on this role. Trust me, there were times when I almost gave up" (KIF17)*
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7 Women may worry about bringing shame on their communities or experience shame or guilt
8 if they speak about FGM to service providers or other 'outsiders' (KIF17; KIF16)[35],
9 particularly as some communities are explicitly told not to speak about FGM (KIF17). Trust-
10 related barriers were thus common between communities and professionals (KIF07; KIF04),
11 particularly within child protection (KIF18) or health services, where usage of interpreters
12 could compound trust issues (KIF16; KIF17). Taking time to build trust was therefore deemed
13 important
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17 *'It's not a case of turning up with knowledge, but of starting off with the knowledge of*
18 *communities themselves, then building something together' (KIF02)*
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22 Gender norms and power dynamics within potentially-affected communities were identified
23 as potential barriers, with several participants highlighting the importance of working with
24 men and women separately before bringing them together if appropriate (KIF04; KIF07).
25 While gender oppression was a structural barrier experienced by women globally, "*its*
26 *manifestation differs according to culture, country and social grouping*"[29], thus affecting
27 which avenues were open to women to challenge or engage with FGM and other aspects of
28 their lives[32, 36].
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34 *Structural:* Lack of understanding among professionals of the value and potential role of
35 communities was highlighted as a key barrier to their involvement in interventions. Key
36 decision-makers and service providers would need to change the ways in which they work to
37 ensure that communities were actively involved and heard. One participant provided an
38 example of statutory professionals in Bristol who developed alternative ways of engaging
39 with communities including attending community events, holding informal consultations, and
40 making meetings and meeting space more equitable and community friendly (KIF18). Lack of
41 compensation for travel and childcare expenses was cited as a barrier by several
42 participants, including a lack of understanding by some professionals of why such expenses
43 would even be required (KIF06; KIF17; KIF18).
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49 *'It still feels like there is a need to explain the added value of communities to the*
50 *powers that be.'* (KIF18)
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53 *Sustainability:* Participants in different contexts raised concerns about the sustainability of
54 FGM interventions, particularly those at community level that required long-term investment.
55 Some indicated that although community-led organisations were often approached for their
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3 expertise, they were rarely funded for this advisory role (KIF15) and that significant
4 government funding was needed (KIF06; KIF15). Others highlighted the need for longer-term
5 investment in implementation and action beyond developing protocols, frame-works, and
6 action plans (KIF15; KIF03). Several noted that much of the work of community organisations
7 was not financially valued, with one participant stressing how important it was to recognise
8 the challenging nature of this work, which is '*under-valued and under-resourced*', and
9 questioning how long community members could continue to volunteer in such challenging
10 roles (KIF15).
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16 **Discussion**

17 *Principle findings*

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19 Clear consensus emerged that potentially-affected communities should have a role in all
20 intervention areas and that this was vital to addressing FGM in Europe[1, 15, 27]. Despite
21 this consensus and several examples of good practice (e.g. EU-funded REPLACE and
22 REPLACE 2 programmes, Dutch *Ketenaapak*, the Tackling FGM Initiative), community roles
23 remained inconsistent in FGM interventions and often non-existent in FGM policy
24 development.
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30 Practices ranged from good examples of support for community-led interventions and
31 partnership work with communities to less positive examples of tokenism and non-
32 participation. Most FGM interventions across Europe focused on awareness-raising, and
33 despite examples of good practice noted above, community participation appeared fairly
34 minimal[1, 15]. The extent of community participation was inconsistent between and within
35 countries. While community participation was accepted as vital, participants noted that
36 practices associated with community participation varied enormously. This corresponded
37 with the significant literature highlighting challenges inherent in increasing community
38 participation, e.g. what level of participation[37, 38], '*who participates, in what, and for whose*
39 *benefit*[39], and to what extent government organisations that engage with communities
40 could change to develop truly participatory processes and spaces[40].
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48 The role of communities appeared most developed within prevention interventions, with good
49 practice examples of both community-led initiatives and partnership. Protection-focused
50 approaches were more challenging in terms of participation, as the clear child-protection
51 focus could stigmatise families[1, 7]. Community participation within safeguarding varied,
52 with examples of both effective and emerging roles. Individuals and organisations had roles
53 in building trust and bridging gaps between communities and authorities, though
54 responsibility for managing risk should remain firmly with statutory bodies[27]. While several
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3 community-led organisations delivered a range of services, few examples were found of
4 communities participating in designing, delivering or evaluating statutory services. Good
5 practice examples were identified of community organisations or activists playing a key role
6 in facilitating services access and enabling dialogue within communities to occur[27].
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10 *Implications for policy and practice*

11 Engaging potentially-affected communities in coordinated multi-agency responses appears
12 critical to the success of FGM policies and interventions in Europe. Decision-makers and
13 service providers should invest in community engagement by (i) ensuring that community
14 organisations can participate actively in future interventions and (ii) addressing cultural,
15 structural, and sustainability-related barriers to participation.
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20 Supporting and strengthening community organisations can improve engagement. Bottom-up
21 approaches that enable dialogue within communities appear most successful. Community
22 development support could enable potentially-affected communities to identify their own
23 FGM-related concerns and aspirations and work collectively to identify solutions and take
24 action. This requires long-term investment in community development support and
25 community organisations themselves, to support community-led interventions and
26 meaningful engagement between communities and policy-makers. Any engagement with
27 communities must begin with identifying those communities potentially affected,
28 acknowledging that communities are not homogenous, and engaging with a wide range of
29 groups and community representatives across nationalities and ethnicities. As most women
30 and girls affected by FGM also identify as people of colour, perspectives and lived
31 experiences must be included in development of meaningful policies and services.
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40 Research on FGM interventions across Europe is limited, when compared to levels of
41 activism. Research has focused on clinical care, provision of health services, and attitudes
42 towards FGM. Minimal investigation has been conducted on the role of diaspora
43 communities and their contributions to challenging and responding to FGM. Empowerment,
44 engagement, and participation are frequently mentioned, but rarely critically examined, with
45 little discussion about how to move beyond rhetoric towards putting these concepts into
46 practice. Further research with communities, including participatory methods, appears
47 warranted. Any such research should include the voices of affected women and girls, as
48 those best able to describe their lived experiences and needs and to contribute to the
49 additionally sensitive topics of prosecution and redress.
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56 *Limitations*

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3 This study had three significant limitations. First, this study was exploratory and participant
4 numbers were limited due to time and resource constraints. Second, numbers of participants
5 from potentially-affected communities were limited. While the sensitive nature of FGM may
6 have influenced the engagement of these participants, those we approached had experience
7 of speaking about women's issues and engaging with researchers and policy-makers. Thus,
8 numbers were primarily due to the small-scale and exploratory nature of the research and
9 the lack of time and resources to conduct more extensive community engagement. Further
10 community engagement is needed to expand on issues raised. Finally, focus on European
11 interventions ignored the successfully designed and implemented African interventions, e.g.
12 TOSTAN (www.tostan.org) that offer international benchmarks for changing attitudes and
13 reducing FGM[21].
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19 20 21 **Conclusion**

22 Exploring the role of communities within interventions to address FGM in Europe allowed
23 critical examination of how crucial community voices remain marginalised and could be
24 better heard and supported. "*Without an effective commitment to the participation and*
25 *empowerment of potentially-affected communities, policy-makers and practitioners will not*
26 *identify the actual risks experienced by diaspora girls and women in Europe or develop*
27 *effective interventions, and risk further marginalising those community voices that are the*
28 *most effective advocates for change*"[6]. Results demonstrate that it is possible to work
29 alongside potentially-affected communities, benefitting from community perspectives and
30 expertise, to develop meaningful partnerships and support community-led interventions.
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37 **Declarations**

38 *Conflict of interest*

39 None declared.
40
41

42 *Author contributions*

43 EC contributed to study design, data collection and analysis and drafted the manuscript. NM
44 contributed to study design, data analysis, and manuscript writing. HB contributed to study
45 design, data collection and analysis, and critically reviewed the manuscript. NH contributed
46 to study design and data interpretation and critically revised the manuscript. All authors
47 approved the version for submission.
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53 *Acknowledgements*

54 Special thanks to all key informants, particularly women from potentially-affected
55 communities, for their invaluable insights.
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Funding

This work was supported by the Scottish Government Equality Fund and Rosa FGM Small Grants Programme for funding research.

Data sharing

Anonymised dataset and coding are available on request in accordance with LSHTM institutional data management policy.

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Tables

Table 1. Key definitions

Female genital mutilation	All procedures that involve partial or total removal of the female external genitalia, or other injury to the female genital organs for non-medical reasons (WHO, 2016)
Community	A community of identity has a common bond based on ' <i>geography, identity or interest</i> ' [10]
Community development	Community development enables people to work collectively to bring about positive social change. This long-term process starts from people's own experience and enables communities to work together to: <ul style="list-style-type: none"> • identify their own needs and actions; • take collective action using their strengths and resources; • develop their confidence, skills and knowledge; • challenge unequal power relationships; • promote social justice, equality and inclusion; to improve the quality of their own lives, the communities in which they live and societies of which they are a part [10]
Participation	Policy-making and practice development around violence against women is shaped by the experiences, needs and views of those affected by FGM [6]
Potentially-affected community	A diaspora community from one of 29 countries identified by UNICEF, in which FGM practices are concentrated, i.e. Somalia 98%, Guinea 96%, Djibouti 93%, Egypt 91%, Eritrea 89%, Mali 89%, Sierra Leone 88%, Sudan 88%, Gambia 76%, Burkina Faso 76%, Ethiopia 74%, Mauritania 69%, Liberia 66%, Guinea-Bissau 50%, Chad 44%, Cote d'Ivoire 38%, Kenya 27%, Nigeria 27%, Senegal 26%, CAR 24%, Yemen 23%, Tanzania 15%, Benin 13%, Iraq 8%, Ghana 4%, Togo 4%, Niger 2%, Cameroon 1%, Uganda 1% [5, 41]
Prevention	Interventions intended to create and/or sustain behavioural and attitudinal change within affected communities [6]
Protection	Interventions intended to protect the individual rights of women and girls who are at risk of or have experienced FGM [6]
Service provision	Service responses to survivors of FGM [6]

Table 2. Participant characteristics

ID	Role/Title	Location	Interview type
KIF01	University professor	Spain (Skype)	KII
KIF02	NGO worker	France	KII
KIF03	NGO worker	Netherlands	KII
KIF04	Teacher	England	KII
KIF05	Government minister	Netherlands	KII
KIF06	University professor	Belgium	KII
KIF07	Community activist	Ireland (Skype)	KII
KIF08	Medical professional	England	KII
KIF09	University professor	France	KII
KIF10	INGO worker	EU	KII
KIF11	Solicitor	Scotland	KII
KIM12	Police officer	England	KII
KIF13	Police officer	England	KII
KIF14	Legal professional	France	KII (unrecorded)
KIF15	NGO worker	England	KII
KIF16	Medical professional	Scotland	KII
KIF17	Community activist	Scotland	KII
KIF18	Community activist	Scotland	KII
EG1	9 policy/practice participants	Scotland	Group interview
EG2	9 policy/practice/community participants	Scotland	Group interview
EG3	10 policy/practice/community participants	Scotland	Group interview
CG1	4 community activists	Scotland	Group interview
CG2	4 community activists	Scotland	Group interview

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

YOU MUST PROVIDE A RESPONSE FOR ALL ITEMS. ENTER NA IF NOT APPLICABLE

Item	Guide questions/description	Response or reporting page
Domain 1: Research team and reflexivity		
<i>Personal Characteristics</i>		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	(p 5)
2. Credentials	What were the researcher's credentials (e.g. PhD, MD)?	MSc, DrPH
3. Occupation	What was their occupation at the time of the study?	(p 1)
4. Gender	Was the researcher male or female?	Female
5. Experience and training	What experience or training did the researcher have?	MSc-level social science research methods
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	(p 4)
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	(p 5)
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator (e.g. bias, assumptions, reasons and interests in the research topic)?	(p 5)
Domain 2: study design		
<i>Theoretical framework</i>		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study (e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis)?	(p 5)
<i>Participant selection</i>		
10. Sampling	How were participants selected (e.g. purposive, convenience, consecutive, snowball)?	(p 4)
11. Method of approach	How participants were approached (e.g. face-to-face, telephone, mail, email)?	(p 4)
12. Sample size	How many participants were in the study?	(pp 4-5)
13. Non-participation	How many people refused to participate or dropped out? Reasons?	(pp 4-5)
<i>Setting</i>		
14. Setting of data collection	Where data were collected (e.g. home, clinic, workplace)?	(p 5)
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	(p 5)
16. Description of sample	What are the important characteristics of the sample (e.g. demographic data, date)?	(p 4; p 23)
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	(p 5)
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	NA
19. Audio/visual recording	Did the research use audio or visual recording to collect data?	(p 5)

20. Field notes	Were field notes made during and/or after the interview or focus group?	(p 5)
21. Duration	What was the duration of the interviews or focus group?	(p 5)
22. Data saturation	Was data saturation discussed?	(p 5)
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	NA
Domain 3: analysis and findings		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	(p 5)
25. Description of the coding tree	Did authors provide a description of the coding tree?	(p 5)
26. Derivation of themes	Were themes identified in advance or derived from the data?	(p 5)
27. Software	What software, if applicable, was used to manage data?	(p 5)
28. Participant checking	Did participants provide feedback on the findings?	(p 5)
<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified, e.g. participant number?	(pp 6-17)
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31. Clarity of major themes	Were major themes clearly presented in findings?	Yes
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes

Once you have completed this checklist, please save a copy and upload it as part of your submission.